

SPOUSE MARITAL ADJUSTMENT AND PATIENT LIFE ENGAGEMENT:
FACTORS IN DIETARY COMPLIANCE
OF CHRONIC HEMODIALYSIS PATIENTS

By

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This is dedicated to:

My wife, Liora, for her enduring love, support,
and encouragement.

My children, Michal, Merav, and Goor, for helping
me become a balanced and happy person.

I love you all.

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PREFACE

Keep a watch on the faults of the patients, which often make them lie about the taking of things prescribed. For through not taking disagreeable drinks, purgative, or other, they sometimes die.

--Hippocrates, On Decorum

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Abstract of Dissertation Presented to the Graduate School
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Scientific accounts of the alarmingly high rates of patient noncompliance with medical regimen, especially among chronic patients, emphasize the importance of better understanding of that costly and self-endangering maladaptive behavior. This study tests the hypothesis that patient noncompliance is related to the level of active patient engagement with his or her environment, and to the quality of the marriage.

Sixty-eight adult chronic hemodialysis patients and their spouses were studied. The sample was heterogeneous in terms of race and sex. Spouses completed the Locke-Marital-Questionnaire (LMQ) and provided the life-engagement and demographic data pertaining to their patient spouses. The patients' predialysis

potassium (K) levels (indices of food intake compliance) and interdialysis fluid weight gain (W) (indices of fluid intake compliance) for the previous three months were matched with the respective questionnaires. A significant and potent global relationship was found between the optimal linear combinations of the compliance measures and the investigated independent variables: age, years of education, time on dialysis, number of medications taken, weekly hours spent in vocational, recreational, and social activities, and the spouse's LMQ score. The LMQ score was found to be the most potent single independent variable. It was negatively related to the dietary compliance scores except to K. The K levels stood out as being related to neither the W levels nor to the linear combination of the independent variables, which in turn, were significantly correlated with W. The number of weekly hours the patients spent in vocational, recreational, and social activities (life-engagement) were found to be variables of significant contribution to the total covariance accounted for in the computed multiple regressions.

Additional analysis discovered that black spouses, especially black males, scored significantly less on the marital adjustment scale than white spouses. Black patients were reported to be significantly less actively engaged in the investigated activities than whites, especially when vocational engagements were compared.

It has been suggested that the onset of the chronic illness has disrupted the patients sense of control to the extent that some were never able to fully regain it. It was also suggested that those patients who have not regained their sense of control are those who are relatively disengaged from their environments and less in control over their dietary regimen.

Further documentation of the relationship between life-engagement variables and patient compliance is needed to validate the suggested theoretical constructs.

CHAPTER I INTRODUCTION

Prior to the twentieth century, patients and practitioners had considerably less control over matters of medical concern than is currently the case. Since 1900, patterns of mortality have changed significantly in the Western hemisphere. Primary health concerns have shifted from acute infectious epidemics to chronic, degenerative conditions (McKeown, 1976; Torrens, 1978).

Modern medical science is progressing quickly. Lives that would have ended by natural causes much earlier are now prolonged by a variety of mechanical equipment. Patients may indeed survive longer with serious, chronic illnesses, but they are forced into severely restricted lives, absolutely dependent on these nonhuman devices. It often becomes unclear whether the medical equipment is there to accommodate the patients or whether it is the patients who have to alter their lives to fit its demands and the treatment it provides. The task of coping with chronic diseases, the adherence to long-term medical regimen, and the task of making a good emotional adjustment to the condition place stressful demands on the patient, often calling for an inner strength and resourcefulness that is itself chronically sapped by the illness.

Need for the Study

Millions of people, worldwide, are suffering today from some kind of a chronic disease. In the United States alone about 50,000 people are afflicted with some form of renal disease. Approximately 42,000 of these require hemodialysis treatment for life maintenance (Hunt, 1979). The annual cost of treatment for a medically complying hemodialysis patient is estimated to be \$28,000 - \$35,000, and much higher for non-complying patients.

The tremendous physical, emotional, and financial cost (including the high death rate) brought about by these diseases is, in part, avoidable. Nevertheless, a significant proportion of the morbidity and mortality in our society does occur prematurely. Much of it may even be completely preventable (Di Matteo & Di Nicola, 1982). Considerable evidence suggests that morbid and mortal conditions might be prevented by patients' control of their personal habits (Fuchs, 1975; Knowles, 1977). The problem of patient compliance has plagued medicine in modern times. This problem--patient noncompliance--involves patients' failure, due to resistance and/or unwillingness, to fulfill the requirements of a prescribed medical regimen or to engage in preventative health care. In the case of chronic hemodialysis, abuses of the strict medical diet result in frequent hospitalizations, translating into skyrocketing health care costs which patients, mostly of

low socio-economic-status (SES), can rarely afford. This problem seems to be alarmingly prevalent. Sackett and Snow (1979) suggest that the average general compliance for short-term regimens is 62% (of the patients). Patients prescribed medication regimens for long periods of time for prophylaxis or for chronic diseases appear to be less compliant than those on short-term regimens (mean compliance rate of 54%). With such a troublingly low compliance rate, it would be safe to conclude that hundreds of thousands of Americans, certainly millions of persons worldwide, are currently risking and actively endangering their lives by failing to adhere to their prescribed medical regimens.

Patient noncompliance involves a number of social and behavioral science issues from thoughts, feelings, and measurable traits to interpersonal relationships to the influence of social class and culture. When examining some of these issues, one cannot help but infer the importance of the patient's capacity to be personally responsible, to exercise self-control and to be self-determining (Becker, 1969; Wallston & Wallston, 1978). It is assumed that while being motivated and cared for by the family and by the practitioner are of crucial importance, the patient remains in ultimate control of his or her own health actions.

This study is designed to promote the understanding of some important correlates of the phenomenon of patient non-compliance. It is believed that such understanding could help the medical and health administration establishment choose some promising directions towards improving the quality of life of hundreds of thousands of chronic patients and their families.

Purpose of the Study

The purpose of this study is to determine the relationships between expressions of a self-determining lifestyle, or what was termed here as "life engagement," the quality of marriage, and measures of patient compliance with a medical regimen.

According to Epstein and Cluss (1982), compliance rates in a large majority of all investigations must be considered to be underestimates of the problems, due to sample-selection procedures. Most studies include in their sample only patients willing to participate in a research project and only those who are compliant enough to be part of the regular clientele of a medical clinic.

Another major problem in the compliance research is the use of unreliable, inaccurate, or potentially falsified compliance data (e.g., Gordis, Markowitz, & Lilienfeld, 1969; Mattar, Markello, & Yaffe, 1975; Tinkelman, Vanderpool, Carroll, Page, & Spangler, 1980). The chronic hemodialysis setup is ideal for studying the problems of noncompliance and abuse of

medical regimen (De-Nour & Czaczkes, 1972). The treatment is chronic, the contact with the patients both prolonged and intensive. Patients cannot skip treatments or go to another physician. Their mobility is considerably limited, due to the need to be hemodialyzed three times a week.

Another purpose of the present study is to eliminate some of the methodological weaknesses discussed by Epstein and Cluss (1982) by avoiding patients' noncompliance with the investigation proper. This is done by gathering information from patients' spouses about certain behaviors and habits of the patients. The spouses' perception of the patients and the marriage is regarded as an expression of the quality of the marriage. Another methodological improvement is the use of valid and reliable methods of assessing compliance. Investigation of the phenomenon of compliance in chronic hemodialysis will correct previous weaknesses because the medical regimen of dialysis is clear cut and because the abuse of it is easily measured.

CHAPTER II REVIEW OF THE LITERATURE

Aspects of Hemodialysis

Before attempting to review the compliance literature, a description of the physical and psychological aspects of the hemodialysis experience is presented.

The Medical Process

Hemodialysis is a way of life that absolutely depends upon the artificial kidney dialysis process. To stop dialysis treatments means death by uremic poisoning within days or weeks as the wastes and toxins slowly build up within the body. There are four basic ways to sustain therapeutically the life of patients with chronic renal failure: hemodialysis in a hospital or a clinic, home dialysis, continuous ambulatory peritoneal dialysis (CAPD), and kidney transplantation.

Hemodialysis in the clinic. The artificial kidney uses the principle of dialysis. It filters out the waste products and excess fluid from the patient's bloodstream, a job which the natural kidneys have been failing to do. The first step in getting ready for dialysis is to have a vein and an artery surgically joined in the patient's arm, to enable the connection of the patient to the hemodialysis machine. The

patient then comes to the clinic, is weighed, blood tested, and then connected to the machine.

Treatment "on the machine" requires the patient to be hooked up two or three times a week for five to eight hours or more at a time. The patient usually reclines in an easy-chair or hospital bed while the blood flows out of a shunt in the arm, through transparent plastic tubes, to the machine which dialyzes it, and then back through plastic tubes to the shunt. Although the machine requires monitoring, the patient is relatively passive throughout the process.

Home dialysis. This is essentially an identical process, in which the procedures are carried out by the patient and his or her spouse, parent, or other aid.

CAPD. This process of hemodialysis is ambulatory. This method uses the ability of the peritoneum (the lining of the abdominal cavity) to separate the waste products. Under CAPD, the dialysis process is a continuous one and permits the patient to be either ambulatory or asleep while dialysis is taking place. To prepare for CAPD, a plastic tube is inserted through the abdominal wall just below the navel and fixed in place. A plastic bag, filled with a solution similar to that used in the hemodialysis machine is connected to the tube.

The solution then flows from the bag into the abdominal cavity. The empty bag is folded up and placed beneath the clothing. After about four to six hours, the empty bag is reconnected to the plastic tube. The solution, now containing the waste products separated by the peritoneum, flows back into the bag and a new bag is attached.

Physical Effects of Hemodialysis

Halper (1971) has noted the fragility of the hemodialysis patients' medical status and it is this fragility which makes it virtually impossible for patients to predict when they will feel well or ill and is a source of great frustration when making plans. There are complications with shunts quite often and skin becomes discolored after a while.

Halper (1971) documents how hemodialysis creates what is basically a temporary Organic Brain Syndrome characterized by decreases in memory and reality-testing. The EEG deteriorates and the patient shows signs of the Disequilibrium Syndrome: restlessness, headache, nausea, and increased blood pressure.

Calland (1972), furthermore, reports how the process of hemodialysis leads to cerebral edema, fatigue, dyspnea, and muscle weakness. Drowsiness, dizziness, and nausea may accompany the rapid changing of the electrolytic balance in the patient's system. Sometimes there is a sick feeling that emerges a day before dialysis treatment as the waste

products build up in the patient's body and the patient may experience a wasted-out feeling for a day after dialysis while the body stabilizes.

Menzies and Stewart (1968) report that all seven of their patients intermittently showed a delirious or subdelirious reaction, suggesting that episodic organic cerebral dysfunction occurs during hemodialysis. However, De-Nour, Shaltiel, and Czaczkes (1968) note that evidence from clinical manifestations, psychological tests, and EEG suggests that many patients develop brain dysfunctions of a more chronic nature.

The Psychological Experience of Hemodialysis

Viederman (1974), working from a psychoanalytic framework, suggests that the machine and the restricted diet "inevitably" evoke conscious or unconscious fantasies of the treatment that related to the earliest developmental stages and have to do with the interaction between mother and child and with total helpless dependency. The treatment, he claims, requires regression to this earliest stage.

Lefebvre, Norbert, and Crombez (1972), on the basis of psychoanalytic impressions from following 35 patients for three years, found that patients' method of relating to the machine was to use the method of internalization known as incorporation (in contrast to introjection) with the result that the boundaries between the self and object become

blurred. Furthermore, patients do not incorporate the machine, but rather feel incorporated by it.

Abramson, Garg, and Angell (1976) report how integral a part of the self-image the machine becomes for patients. In a Draw-a-Person task patients with chronic renal failure drew pictures that either included a shunt in the arm (or, occasionally, the leg) or hid the arm in some fashion, such as with a sleeve or putting the arm behind the back.

Wright, Sand, and Livingston (1966) note that after a while on hemodialysis, hook-up to the machine comes to have a low degree of associated stress through familiarity rather than through denial. However, they and other writers have noted the continued anxiety about accidents and complications with the shunt (Freyberger, 1973; Halper, 1971).

Two very important aspects of the medical regimen are the diet and fluid restrictions. The compliance with these dietary restrictions is the focus of this study. Calland (1972) complains bitterly of how the restrictions on sodium and potassium make food unpalatable, but even that restriction is not as bad as being held to 800 ml total intake of fluids per day. Czaczkes and De-Nour (1978) also note how stressful the fluid restriction is, as well as the fact that for unknown reasons patients are thirsty all the time, which makes restriction just that much more difficult.

Perhaps the most important psychological stressor to be identified in the early psychiatric studies of hemodialysis is the conflict about dependency (Abram, 1968; Cramond, Knight, & Lawrence, 1967; De-Nour et al., 1968; Freyberger, 1973; Goodey & Kelly, 1967; Halper, 1971; Moore, 1972). This dependency upon staff, family, and machine requires the patients to regress. Although this regression sets up enormous conflicts in some patients, other patients enjoy the regression to such dependency (Levy, 1976; Reichsman & Levy, 1972). However, even in this latter case dependency is a central issue, for Reichsman and Levy (1972) suggest that such enjoyment of dependency is due to the fact that dependency needs of these patients were not sufficiently gratified when they had to function independently. For those patients whose dependency needs had not been frustrated, the enforced dependency of hemodialysis is a very real threat (De-Nour & Czaczkes, 1976). Such dependency often leads to feelings of rage that constitute another area of conflict and psychological stress.

There are changes in body image that constitute another area of psychological stress. Although in the first decade of hemodialysis there were reports of rather bizarre feelings about, and relations to, the machine as part of the patient's

body (Abram, 1970; Cooper, 1967), Czaczkes and De-Nour (1978) report that such extreme machine related body image disturbances are rare and are no longer a central issue.

Preoccupation and even shame of the shunt in the arm are reported by some (De-Nour et al., 1968; Lefebvre et al., 1972) while concern with general appearance is reported by others (Short & Wilson, 1969). Important as these concerns are, Czaczkes and De-Nour (1978) emphasize that the major issue of body image for dialysis patients is the loss of urination. In an early report De-Nour (1969) described the psychological importance of unriation and the stress associated with the loss of this function which led some patients to have "phantom urination."

Another aspect of the alteration in body image and functioning is the usually drastic alteration in sexual relations and self-perception. Due to decreased libido, fears about injuring the shunt site or acceptance by the partner, and fears resulting from lower self-esteem, patients report decreased frequency of intercourse and a high rate of total or partial impotence (Abram, Hester, Sheridan, & Epstein, 1975; Foster, Cohn, & McKegney, 1977; Steele, Finkelstein, & Finkelstein, 1976).

A fourth major area of psychological stress in chronic hemodialysis is the threat of death. Chronic renal failure is a terminal illness, but how long patients survive on

hemodialysis is dependent on many factors, most important of which are compliance with the medical regimen and the presence or absence of other medical problems. Although the threat of death can be a very significant stressor for some patients (Sand, Livingston, & Wright, 1966; Wijsenbeck & Munitz, 1970), other stresses such as job changes and marital problems come to have even greater significance (Wright et al., 1966) and lead to the demoralizing bind that Beard (1969) describes as "fear of death and fear of life."

Another major source of stress involved in chronic hemodialysis is the many losses and restrictions placed on the patient that necessitate major alterations in lifestyle. Wright, Sand, and Livingston (1966) and Calland (1972) note that patients faced the actual or threatened loss of membership in groups; the failure of plans or ventures; loss of homes, possessions, or financial status; loss of job or occupation; and other small details of a way of life.

The Problem of Compliance

Nearly all medical encounters culminate in advice to the patient. It is commonly accepted that these recommendations are made in the interests of the patient's own good. In giving medical advice, clinicians call upon many advances in patient care that have brought medicine to the scientific forefront

in recent years. Patients with heart disease, once sure to die in early middle age, are now offered treatments that prolong their lives and restore in some measure their health and vigor. Diabetic patients can now enjoy essentially normal and productive lives by faithfully taking insulin and regulating their diet and exercise. Even chronic renal failure patients can technically lead a relatively normal life between treatments by undergoing periodic hemodialysis and adhering to a strict diet.

Attempts by medical practitioners to gain compliance, adherence, or self-control from their patients very often meet with failure. Deliberately or not, many patients ignore, totally forget, or erroneously implement their medical regimen. Their treatment recommendations can involve such diverse actions as following a restricted diet, taking a pill daily, or returning for follow-up appointments.

Occasionally, patients creatively substitute their own particular treatment regimen in place of the one that was medically prescribed (Di Matteo & Di Nicola, 1982). In essence, noncompliance is the patient's failure to fulfill the clinical prescription (Haynes, 1979).

Empirical studies of patient compliance have shown that it occurs among patients of all ages, social classes, and ethnic groups and among patients participating in various forms of health care delivery. Noncompliance is a common

response of patients who are without symptoms, only slightly ill, or already seriously ill (Haynes, 1979; Sackett & Snow, 1979). It seems that patient noncompliance thrives wherever and whenever medical advice is generated.

Di Matteo and Di Nicola (1982) ascertain that while complex recommendations, such as those involving major lifestyle changes, are somewhat less likely to be followed than are simpler assignments, adherence to either type of regimen is surprisingly poor. Sackett and Snow (1979) report that regardless of its curative or preventative potential, the regular taking of prescribed medications is avoided to an alarming degree: patients fail to follow short-term medication regimens at rates of 20-30% when the regimen is preventative. With lifetime medication regimens and with long-term behavioral scheduling, such as eating a restricted diet to prevent or control symptoms in diabetes, hypertension, or chronic renal failure, noncompliance is usually about 50% initially and increases as the therapy continues (Haynes, 1979; Luntz & Austin, 1960; Procci, 1978; Sackett & Snow, 1979).

Although this study focuses on chronic illness, it should be mentioned that compliance is also very important in preventive health measures. Despite knowledge of health risks for cancer, heart disease, stroke, and other serious illnesses,

and despite direct medical advice against risky behaviors, people continue to smoke, drink too much, and avoid exercise (Surgeon General, 1979).

Forms of Medical Regimen

Medical recommendation can take a number of forms. Clinicians may prescribe certain behaviors such as exercise to their patients, or they may proscribe behaviors such as smoking. Medical prescriptions and proscriptions may be made for short-term or for long-term periods. The practitioner's intervention may also occur at any point in the disease process and so it can take one of three basic forms of prevention: primary, secondary, or tertiary (Caplan, 1970).

Primary prevention involves the prevention of disease before any symptoms occur. It may involve taking such action as maintaining normal weight, exercising, not smoking, participating in preventive medical screening and immunization.

Secondary prevention involves the enactment of some preventive regimen by a person who has been defined as "at risk" (e.g., the yearly electrocardiogram taken by a man who has a family history of heart disease).

Tertiary prevention involves strategies designed specifically to control the progress of disease (e.g., the self-injection of insulin by the diabetic or the dietary restrictions and hemodialysis treatments by the chronic renal failure patient).

This study is going to focus on noncompliance with tertiary prevention, a behavior that bears immediate life-endangering complications, especially in life-threatening diseases, such as in chronic renal failure.

Definitions of Compliance

Any detailed analysis of compliance should consider the meaning of the word "compliance." Compliance has been defined in many different ways, with definitions ranging from strict to loose interpretations of the term. The dictionary definition of compliance suggests "yielding as to request, wish, desire, etc., a disposition to yield to others; complaisance" (Webster dictionary, 1977).

Haynes' (1979) definition which will be adopted in this study, sees compliance as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (pp. 2-3).

Others add to this definition by including as components of compliance, knowledge of the correct name of the medication, attendance at follow-up appointments (Becker, Drackman, & Kirscht, 1972; Nessman, Carnahan, & Nugent, 1980), and filling prescriptions (Becker et al., 1972; Haggerty & Roghmann, 1972).

Researchers who have studied health behavior have employed a number of other words in lieu of compliance--terms such as

adherence, obedience, cooperation, concordance, collaboration, and therapeutic alliance. Sackett and Haynes (1976) have argued that such terms are best used interchangeably, whereas others (e.g., Di Matteo & Friedman, 1979) have suggested that compliance reflects an overtly authoritative approach to patient care which implies an obligation on the part of the patient to follow the practitioner's orders blindly. Dunbar and Stunkard (1977, p. 392) justify the use of the term "adherence" over "compliance" by reference to the Whorf-Sapir hypothesis that "the nature of the words used to describe events has a powerful influence upon how those events are understood."

For the sake of consistency, the most accepted term in the literature will be used, namely, compliance. The terms adherence and compliance will be used interchangeably in this study without any implications to the varying power relationships between doctor and patient.

Problems of Assessment and Measurement of Patient Compliance

Compliance is a very difficult parameter to measure accurately. The study of compliance, therefore, suffers from some serious methodological issues, arising from the problems of assessment.

First, patients do not always tell the truth. They typically report that they have followed their physician's

advice when, in fact, sometimes they have not. Second, the medical regimen, for medication-taking, for example, can be more complex than many may suspect. Failure to comply with medication-taking may include omission of doses, taking medication for the wrong reason, errors in dosage or timing of sequence, and discontinuing therapy before the end of the recommended course (Hagerty & Roghmann, 1972).

There is ample evidence to the effect that physicians typically overestimate rates of compliance among their patients and that they are inaccurate in identifying noncompliant individuals (McClellan & Cowan, 1970; Moulding, Onstad, & Sbarboro, 1970; Mushlin & Appel, 1977; Norell, 1981). In their review of the compliance literature, Sackett and Snow (1979) noted that the gap between the regimen prescribed by the clinician and that adhered to by the patient is often distressingly wide and that, tragically, the clinician is often the last to know about noncompliance.

The need for secretive or probing strategies (such as pill counts, direct urine or blood assay, questioning a family member, and others) to gauge patient compliance has been seriously criticized by some compliance researchers (Sackett, 1979; Stone, 1979). They have noted that factors in the practitioner-patient relationship may interfere with the

accurate interview reporting of patients' compliance with their medical regimens.

Di Matteo and Di Nicola (1982) have argued that open and successful disclosure about compliance is both a product of and a catalyst for a practitioner-patient relationship of high quality. It is evident, however, that even when focusing specifically on omission of doses, for example, the ability to make knowledgeable assessments of the percentages of prescribed medication taken is based in large part on the instrument technology available to the practitioner or compliance researcher.

Epstein and Cluss (1982) argue that the ideal situation would be to be able to measure medication intake directly, so that a patient would be considered compliant only if a dose were taken within the time interval specified by the drug regimen, or if he or she closely adhered to the prescribed food and liquid restrictions (directly measured by weight gain, blood and urine assays). According to Epstein and Cluss's compliance literature survey, this specificity of measurement has been performed in only one published account (Norell, 1979).

Indirect Methods of Assessing Compliance

Self-Report

Asking the patient if he or she has taken the prescribed amount of medication, or has followed the prescribed diet,

seems to be the most obvious method of indirect assessment. This method was employed primarily by earlier researchers (Malahy, 1966; Mohler, Wallin, Dreyfus, & Bakst, 1956; Schwartz, Wang, Zeitz, & Gross, 1962). Others have reported that many patients simply overreport self-administration of oral medication (Bergman & Werner, 1963; Gordis, Markowitz, & Lilienfeld, 1969). It seems, then, that more accurate techniques are necessary, at least where the risk of noncompliance to those who misrepresent themselves as compliers is great.

Therapeutic Outcome

This indirect measure of compliance may be misleading. According to Sackett (1979), 12% of hypertensive patients investigated were in control without being adherent, while another 34% were adherent but uncontrolled.

Physician Estimate

This method is frequently used by clinicians but may be inadequate for research purposes. Charney et al. (1967), Davis (1968), and Roth et al. (1970) have all found that medical residents or physicians would not estimate levels of compliance in their patients with accuracy any better than chance.

Pill and Bottle Counts

In this potentially more accurate indirect assessment method, the amount of remaining medication is compared with

the amount that would have remained had the patient consumed the medication accurately. The main problem with this method is its being potentially subject to falsification by the patient. Investigators employing this method (Mattar, Markello, & Yaffe, 1975; Moulding, 1961; Tinkelman, Vanderpool, Carroll, Page, & Spangler, 1980) may report unusually high rates of compliance without addressing the possibility that patients may have simply thrown away any unconsumed medication to avoid detection as noncompliers (Epstein & Cluss, 1982). Gordis (1979) claimed that this method may be ineffective for monitoring patterns of noncompliance that may be clinically significant.

Mechanical Methods

Technically sophisticated methods have been developed by Moulding, Onstad, & Nugent (1970) and by Norell (1979). These devices record the number and time sequence of pills removed from prescription bottles, but do not measure medication use. There is no way to rule out the possibility of medications being removed by patients and discarded without appropriate use.

Direct Methods of Assessing Compliance

Tracer and Marker Methods

This is an accurate method based on drug ingestion. Nontoxic FDA-approved agents that are unaffected by the physical

and chemical properties of the urine are usually added to the drugs. The tracers are either added to all the prescribed medication or added to only a portion of the total doses, packaged in a particular known random order within the medication supply (Haynes, 1979; Porter, 1969; Ryan, Carver, & Haller, 1962; Veterans Administration Cooperative Study Group, 1970).

Blood/Serum Assays

Obtaining a blood sample and then performing a serum assay for concentration of the drug in the blood has been recognized as another accurate method of assessing whether patients have ingested medication or violated a prescribed medical diet recently (Eney & Goldstein, 1976; Sherwin, Robb, & Lechter, 1973). This method has a few limitations. Blood drawing has to be well timed because of the particular absorption and metabolism rates of the food or focus drug. The process is expensive, time consuming, and not available for all drugs. The process provides only an approximation of recent pill taking and not an accurate pill-by-pill account of compliance (Epstein & Cluss, 1982).

Urine Inspection or Assays

This is another similarly accurate direct method of testing for compliance based on recent drug, food, or liquid ingestion. The urine assay will detect recent ingestion of medication and

therefore timing is important in this method as well. However, blood/serum and urine assay detection of a substance indicative of abuse of a restricted food could be considered a satisfactory measure of noncompliance. This study will be using direct, objective measures of compliance through measurement of weight gain (fluid intake) and blood potassium levels (abuse of fruit restrictions).

Methodological Problems
in the Study of Compliance

Due to sample selection procedures, compliance rates in a large majority of all investigations must be considered to be underestimates of the problems. Most studies include in their sample only patients willing to participate in a research project (Epstein & Cluss, 1982). It is reasonable to assume that this subgroup of volunteers may be different in motivational or other characteristics, making them more likely to comply as a group than others who are not willing to participate.

Grossly noncompliant patients are weeded out even by investigators who have used as their sample all patients being seen in a clinic, because they cannot include patients who began treatment and never returned. Sackett and Snow (1979) argue for the need for following an "inception cohort" that will include both dropouts and adherents.

This study will attempt to avoid this type of confounding of data, by collecting information about patients and their compliance without their direct participation in the research.

Noncompliance: Explanatory Factors

Explanations generated by researchers and practitioners who have examined the issue of noncompliance fall into three broad categories: intrapsychic, environmental, and practitioner-patient relationship.

Intrapsychic Factors

Goldstein and Reznikoff (1971) and Foster et al. (1973) have argued that dietary abuse among dialysis patients may serve some adaptive function. It was suggested that dietary abuse may be a substitute form of gratification in individuals who have very little reinforcement in their lives (Procci, 1978). Motivational theorists have tended to adopt psychodynamic explanations and suggest that patient resistance can be understood in terms of rejection of authority (Applebaum, 1977; Stimson, 1974). De-Nour and Czaczkes (1972) suggested that low frustration tolerance and primary gain from illness were factors correlated with dietary abuse, while factors that were not correlated with abuse were denial of sick role, acting-out, suicidal intent, and family homicidal wishes. De-Nour and Czaczkes suggested that dietary

abuse was caused by the denial of the sick role, the acting-out of aggression, and the introjection of aggression via depression and suicidal tendencies, as well as by low frustration tolerance and gains from the sick role. They also found out in that study that dietary compliance was promoted by obsessive-compulsive traits. Podell (1975), too, explained noncompliance in terms of disease denial or rationalization of unhealthy behavior. Beliefs and attitudes about one's susceptibility to disease and the severity of potential disease influence compliance, as do patients' beliefs about the cost versus the benefits of treatment (Becker, 1974). Stone (1979) has argued that inaccurate beliefs and misinformation are also relevant to the explanation of noncompliance.

Noncompliance was understood by Brehm (1966) as an active search to restore lost freedom, as well as an attempt to avoid developing a dependency to which past experience has shown them they are prone.

Festinger (1957) has concluded that patients might seek to maintain commitment to a bad decision (a course of behavior such as abuse of liquid or food restriction) by making themselves resistant to persuasion to change their beliefs about it. By resisting therapeutic recommendations, patients may be attempting to balance the power and control in the practitioner-patient relationship. Within this framework, resistance is seen as a

part of the inevitable power struggle between patient and practitioner which is the essence of medical care (Freidson, 1970).

Personality

It seems that empirical research on the relationship between patient personality and compliance with preventive and rehabilitative treatment regimens is relatively sparse. In addition, few empirical studies exist for each individual personality characteristic that has been examined. Thus, it is difficult to assert the stability of any particular finding. The evidence does not seem to be strongly in favor of patient personality as an important factor in compliance. Neither, however, are personality traits totally uncorrelated with compliance behavior.

A major conceptual problem exists in many of the studies of personality and compliance. Many have employed as their measure of "personality" not objective, standardized personality tests, but rather evaluations made by practitioners and interviewers. These evaluations were, of course, likely to reflect the evaluator's stereotypes of patients who are noncompliant. It becomes difficult, then, to determine whether the ratings of personality were predictors of noncompliance or reflections of the evaluator's expectations.

A somewhat different methodological problem arises with research which has used pencil and paper questionnaires. These

investigations have omitted all those patients who refused to cooperate with the researchers and did not fill out the research questionnaire. In research which focuses on compliance, this might include some serious confounding of the data. The role of patient personality in compliance with treatment, therefore, still remains unclear.

Attitudes and Beliefs

Although noncooperative patients might confound data about the relationship between attitudes and beliefs on the one hand and compliance on the other, it seems that this, nevertheless, is a promising future research direction. The conceptualization of Ajzen and Fishbein (1980) posits that the belief component is antecedent to the affective-attitudinal component and that the behavioral orientation (intention) is an outgrowth of attitudes and social norms. Serious doubts have been raised regarding the ability of attitudes to correlate highly with behavior (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975).

Researchers have attempted to reconcile the relatively low correlation between the two by conceptualizing the attitude-behavior relationship in a somewhat more complex way. The theory of Reasoned Action (Fishbein & Ajzen, 1975), for example, is currently one of the most promising models offering a general explanation and prediction of behavior (including health

behavior). The theory holds that people decide to engage or not engage in a given action by carefully considering its implications. Beliefs are thus considered central to predictions of health behavior. The Health Belief Model which has been developed from Ajzen and Fishbein's theory (Becker, 1974; Rosenstock, 1966) hypothesizes that people seek and comply with health-care regimens only under certain specific conditions. They must possess some minimal level of health knowledge and motivation toward health. They must also believe that they are vulnerable to a threatening illness condition. They must be convinced that the treatment can be efficacious and that the cost of such control (in the form of actions) is not too high in view of the benefits.

The phenomenological orientation on which the Health Belief Model is based asserts that current dynamics within the individual (rather than historical issues) affect health behavior. In the framework of Kurt Lewin's life-space theory (1951), it was assumed that the individual gravitates toward regions which are positively valued (relief or prevention of disease) and away from regions which are negatively valued (disease).

Locus of Control

An important component of the previously described Health Belief Model (Becker, 1974) involves the individual's belief

in the efficacy of health-oriented actions. The success of a program of preventive health behavior and the achievement of compliance with a treatment regimen depend, to a significant degree, on the target individual's belief that his or her state of health is within the realm of control (be it the individual's control or that of the practitioner). The belief in a certain degree of correlation between one's behavior and its outcomes is the basis of the notion of locus of control, derived from the social-learning theory of psychologist Julian Rotter (1954). Rotter's theory states that a person's potential for enacting a behavior (for example, his intention to follow a prescribed diet) is jointly affected by his expectancy that the behavior will lead to a particular outcome (e.g., that it will control dangerous changes in the electrolyte composition of the blood and blood pressure stability) and the value of that outcome.

The value of an outcome such as controlling blood pressure or preventing stroke is likely to be at least partially dependent upon the person's belief in the severity of the disease and his or her own susceptibility to its consequences. The value is also dependent upon the person's motivation toward and concern for health as well as on his or her belief in the degree to which benefits of the health behavior (e.g., peace of mind) outweigh the costs (e.g., controlling the drinking behavior while feeling thirsty).

As Becker (1974) noted, however, one aspect of perceived benefits does involve components of a "value X expectancy" theory of health behavior, although these are not completely developed or explicitly spelled out. Locus of control is a complex psychological construct that has been well studied both generally and as it relates to health specifically. The concept is important because in order to understand fully the importance of beliefs in the efficacy of care, we must first examine the notion of generalized expectancy. This involves the expectation that reinforcement is under one's own individual control ("internal locus of control"), or, in contrast, the expectation that reinforcement is under the control of outside forces such as fate, chance, or powerful others ("external locus of control").

Many studies have shown that individuals with an internal locus of control (who generally believe that reinforcement is contingent upon an individual's own behavior) are more likely to be nonsmokers than smokers (James et al., 1965) and to quit smoking or modify their smoking behavior (Steffy et al., 1970).

Research on the use of contraception and weight loss also suggest that internal locus of control is an important factor in adherence (Lundy, 1972; MacDonald, 1970; Phares, 1976), reducing cigarette smoking (Manno & Marston, 1972; O'Bryan, 1972), greater reported seat-belt use (Williams, 1972a), and

preventive dental care (Williams, 1972b). Among already ill patients, locus of control has been a good predictor of sick-role behavior (Seeman & Evans, 1962). Wallston and Wallston (1978) report that the relationship between locus of control and compliance behavior is somewhat weak and sometimes equivocal. As noted earlier, this is probably because locus of control must be combined with the value of health and with social-normative factors in order for it to have a substantial degree of predictive power.

In the initial study of locus of control in dialysis patients, Goldstein and Reznikoff (1971) noted that in the study by Abram et al. (1971) on suicidal behavior 117 of the 192 suicides were accomplished by "food-drink binges." Instead of interpreting this bingeing as suicidal, Goldstein and Reznikoff suggested that in an attempt to cope with the continuous responsibility and anxiety of keeping one's self alive by following a rigid treatment regimen, dialysis patients adopt an external locus of control which allows them no longer to perceive their behavior as life-sustaining, and thus a large, threatening area of responsibility is avoided. The investigators found that dialysis patients had a significantly greater locus of control than did a control group of patients in the convalescent stage of a minor medical condition.

One of the dynamics operating in the condition of dialysis patients is that they do not expect a return to health as treatment progresses, and so their sense of mastery never returns. The authors further note that although this sense of an external locus of control through which patients perceive their behavior as having little or no effect on their condition can help them avoid the constantly intruding reminders of their tenuous hold on life, it can also have disastrous consequences when their cooperation is essential for survival. If the patients perceive their behavior as correlated to their condition, it increases the likelihood that they will reject their role in treatment. However, an alternative hypothesis for binging is that it is a rebellion against the rigid control that the dialysis treatment imposes upon them. That is, it may be an aggressive acting-out rather than a helpless act.

In a study that investigated the relationship between locus of control and adjustment to dialysis, Poll and De-Nour (1980) also found an overall mean locus of control score (10.95) which they interpreted as being indicative of an external locus of control. This is similar to results in other studies (Foster, Cohn, & McKegney, 1977; Goldstein & Reznikoff, 1971; Kilpatrick, Miller, & Williams, 1972; Todd & Kopel, 1977; Wilson, Muzekari, Schneps, & Wilson, 1974).

Poll and De-Nour (1981) split their sample at the median to yield one group with internal locus of control ($\bar{x}=8.25$) and the other with external locus of control ($\bar{x}=13.65$) and compared the two groups on the following aspects of adjustment: (1) compliance with food and dietary restrictions; (2) vocational rehabilitation, with patients who were working at least half-time being rated as working, while those rated as nonworking were usually doing nothing; and (3) acceptance of disability. The results indicated that locus of control was significantly correlated with all three aspects of adjustment. Internals were significantly more compliant and accepting of their disability than were externals; and 75% of the internals compared to 35% of the externals were working. Interestingly, locus of control was not correlated with length of time on dialysis, which suggests that, contrary to Goldstein and Reznikoff's (1971) hypothesis, patients' sense of locus of control does not shift during the course of treatment.

Other Control Theories

Suzanne Thompson (1981) argues in her discussion of the relationship between the sense of control and ability to tolerate pain, that knowing that one has a behavioral response available seems to reduce the aversiveness of the event, lessens preevent anxiety and anticipatory physiological arousal.

Cognitive control has been described by Thompson (1981) as having uniformly positive effects on the experience of an aversive event. Knowing that one has a cognitive strategy lessens, again, anticipatory anxiety, reduces the impact of the stimulus, and improves postevent effects.

A number of theories, hypotheses, and speculations have been posited to explain why one or all of the different types of control should reduce the stress related to an aversive event or condition. These theories can be classified into three different groups: (a) Control as Predictability, (b) Controllability as It Reflects on the Self, and (c) Controllability as a Message about Outcomes.

Control as Predictability. Several theorists have proposed that behavioral control and information reduce stressful reactions because they allow the person to predict some important aspects of the situation and his or her general life condition (Miller, 1979).

Controllability as It Reflects on the Self. Personal control may be beneficial and lack of personal control detrimental because it reflects on the person's self-image. According to de Charms's (1968) theory of personal causation, individuals need to feel a sense of mastery and personal competence in their environment; a lack of control may lead to feelings of incompetence.

Controllability as a Message about Outcomes. Controllability

in a situation may act as a signal about the outcomes that one will receive in that situation. According to the minimax hypothesis proposed by Miller (1979), having control in a situation indicates one will be able to minimize maximum future danger or discomfort.

The issue of control is also expressed in the behavioral-cognitive literature dealing with self-regulation and self-control. It has been demonstrated that people could be trained to control their emotions, thoughts, and behaviors while in an aversive situation or an event they cannot control (Goldfried, 1980; Kanfer, 1980; Rosenbaum & Merbaum, in press; Roskies & Lazarus, 1980). Meichenbaum (1977) was the first among the theoreticians of this field who has suggested the use of the concept "learned resourcefulness." He suggested that once a person has learned how to gain control, his or her perceptions about the aversive condition are changing from perceptions of "learned helplessness" to perceptions of "learned resourcefulness."

Investigators who have used Rosenbaum's (1980) Self-Control Scale (SCS) have found that those who were ranked high on the SCS (high resourcefulness) showed greater pain tolerance (Rosenbaum, 1980), greater tolerance to seasickness (Rosenbaum & Ralnick, in press), and greater control of nail-biting

behavior (Frankel & Merbaum, 1982). Ben-Ari-Smira (1983) has administered the SCS to 53 dialysis patients. She found that the more high-resourceful the subject, the more adjusted he or she was regarding his or her success in restricting fluid intake.

Environmental Factors

This set of explanations for noncompliance includes the effects of the environmental aspects of patients' lives on their behaviors. This section will attempt to describe some of those additional demands on the patients' resources that might lead to noncompliant behavior.

The Cost of Treatment

Financial cost of treatment should probably not be considered as a general determinant of compliance. It has been proven that providing patients with free medications had no effect on their medication compliance (Cody & Robinson, 1977). Brand, Smith, and Brand (1977) have demonstrated that financial affordability of the regimen is a necessary but insufficient condition. Others have shown that prescription of less expensive drugs or treatment method has resulted in an improvement of compliance (Epstein & McCoy, 1975; Haynes et al., 1977).

Access to Medical Care

When the regimen requires keeping referral or follow-up appointments at the medical care facility, certain practical

issues in patients' lives may reduce their capacity to cooperate with the medical regimen. Patients cite the following reasons for not keeping their appointments: a lost appointment slip (Harfouche et al., 1973); confusion over the appointment (Badgley & Furnal, 1961); inability to get a babysitter (Bracken, 1977); lack of transportation (Abernethy, 1976; Alpert, 1964; Harfouche et al., 1973; Mealy, 1975); and weather conditions (Mealey, 1975).

Complexity of the Regimen

The number of medications, treatments, medical or dietary behavior instructions prescribed for a patient has a significant and clear effect on his or her compliance. The more treatments or medications prescribed, the lower the compliance rate (Brand, Smith, & Brand, 1977; Hemminki & Heikkila, 1975; Hulka et al., 1975). Presumably, difficulties arise in coordinating a number of different regimens at once. Furthermore, resources needed in order to follow one regimen may be consumed by attempts to follow another (Di Matteo & Di Nicola, 1982). The duration of treatment also has a consistent relationship to compliance. It decreases with the amount of time the patient has been assigned to the regimen (Romm, Armstrong, & Prior, 1975; Williams & Duncan, 1976). It seems that resources become depleted over time. It is also possible that motivations to follow the medical recommendations dwindle.

Multiproblemicity

A few patients experience an overwhelming number of environmental barriers to the translation of intentions into behaviors, by virtue of their financial status, chaotic social functioning, unemployment, or trouble with the law. Such patients rarely plan ahead because of their "crisis lifestyle." They respond to demand on a day-to-day basis, and thus following a long-term treatment regimen is almost impossible (Golden, 1978).

Social Engagement

There is evidence to the effect that interactions with nonkin occasionally predict health behavior better than kinship ties and that social isolation seems to contribute to patient noncompliance (Baekeland, Lundwall, & Shanahan, 1973; Nelson et al., 1975). Furthermore, there is evidence that social participation and integration positively predict compliance (Pam et al., 1973; Vertinsky et al., 1976; Williams & Lee, 1975). Friends have been shown to have a primarily positive effect on compliance (Bewley & Bland, 1977).

The frequency with which the patient interacts with people outside his or her family has been reported as a good predictor of preventive health behavior (Langlie, 1977). It is, however, still impossible to define which aspects of friendship networks are important to compliance--the frequency

of contacts with friends, the duration of those contacts, the symmetry (balance of control) in the relationship, the accessibility and geographic density of friends, or the intensity and intimacy of friendship (Di Matteo & Di Nicola, 1982).

Family Factors

Family Support

The family constitutes the most important social context within which illness occurs and is dealt with (Litman, 1974). Pratt (1976) has characterized the family as the primary unit in hygiene and health care. In considering the family, the literature usually refers to the intimate social network of the individual--the persons with whom the individual has strong psychological bonds, with whom he or she lives, and from whom the individual derives some identity and self-definition. Despite their diversity, the various family forms do not differ greatly among themselves in many important areas of health care (Wingert et al., 1968).

Family sociologists have traditionally investigated general family issues such as kinship structure and power relationships. However, as Litman (1974, p. 495) pointed out "such major issues as familial response, adjustment, and behavior in health and illness have generally escaped the empirical involvement and theoretical interest of the family sociologist."

Haggerty (1965) has developed a model of family influences on compliance, based on three major theoretical categories:

(1) the family's influence through past medical experiences and attitudes toward health, (2) family influence through internal dynamics and structure, (3) external functions related to others in the community, social mobility, social isolation, and recreational activities.

Family Health Norms

Whether certain symptoms are defined as illness and brought to the attention of the physician will be determined by the consensus of family members and close friends (Richardson, 1970). McKinlay (1973) has reported that individuals consistently report their physical symptoms first to their family members and intimates ("by referral network"). The family has been reported to impose norms for the appropriate use of various remedies such as medication (Osterweis et al. 1979). The family (particularly the wife and mother) is normally the source of illness definition for the members (Aho, 1977; Robinson, 1971).

Finally, family norms influence individual beliefs about the severity of various illnesses, susceptibility to these illnesses, and benefits versus costs of treatment, benefits and costs of continued adoption versus relinquishing of the sick role (Baric, 1970; Becker & Green, 1975).

Family Dynamics

The literature is replete with evidence that illness disrupts the family. Expectations for each person's behavior undergo some change as a result of illness (Klein, Dean, & Bogdonoff, 1968) and family members may find it necessary to develop new patterns of interacting with the patient (Salk, Hilgartner, & Granich, 1972). Certain effects of illness on family functioning may threaten the patients' chances for compliance and successful rehabilitation. A patient's inability to assume his or her former role in the family, for example, may reduce the incentive value of getting well, and thus reduce the patient's tendency to comply (Di-Matteo & Di Nicola, 1982).

Theoretical approaches that emphasize family dynamics in the understanding of self-destructive behaviors such as alcoholism and drug abuse suggest that family environment is an important cause of these behaviors. Along the same lines, recurrent crises in various illnesses may reflect the patient's attempt to improve family members' cooperation with one another and reduce or deflect interpersonal tension in the family (Minuchin, Rosman, & Baker, 1978). Mathis (1964), Lynch, Thomas Mills, Malinow, and Katcher (1974), and Lynch, Paskewitz, Gimbel, and Thomas (1977) have shown that negative or upsetting interactions among family members may have severe negative effects

on health and the outcome of medical care. Vogel and Bell (1968) have noted that the ill member of a family might also serve as the family scapegoat, absorbing the blame for the family's interactional and emotional difficulties which cannot be faced as such. The scapegoat allows the family to channel tensions which would otherwise destroy the family's cohesiveness (Minuchin et al., 1978).

Reactions of Families of Hemodialysis Patients

Huber (1981), in his study of the meaning of adjustment to hemodialysis, suggests that families undergo hemodialysis along with the patients since the lives of the family members and the family as a whole are often radically changed. Many of the restrictions placed on patients are shared by their families, such as the restrictions on travel and physical activities and the financial constriction that is often experienced. Family members and family constellations also undergo psychological change. Speidel et al. (1979) found that not only patients but also their partners described themselves as more attractive, more respected, more capable of pushing through their viewpoint and more interested in their appearance--before beginning hemodialysis. Both patients and their partners currently felt more socially incompetent, and patients saw their partners in a more favorable light than partners saw themselves.

Shambaugh, Hampers, Bailey, Snyder, and Merrill (1967), in a foundational study of emotional disturbances in spouses of home dialysis patients, found spouses stressed by multiple losses and frustrations, particularly the patients' psychological regression and possible death, to which they responded with feelings of deprivation and hostility. While operating the machines spouses not only had to cope with patients' unusual dependency, but also with their own murderous fantasies. Some spouses manifested regressive reactions in the form of serious depression, excessive closeness, denial, and avoidance. Shambaugh et al. (1967) also report much displacement of anger unconsciously directed at patients.

Several writers have reported evidence that unresolved family tensions and difficulties may not only exacerbate an illness but also undermine patient compliance with the treatment regimen (Chen & Cobb, 1960; Mabry, 1964; Minuchin, Baker, & Rosman, 1975), while other studies emphasize the circular process between family patterns and physical illness (Grolnick, 1972; Leigh & Reiser, 1977). A study by Steidl, Finkelstein, Wexler, Geigenbaum, Kitsen, Kliger, and Quinlan (1980) provided evidence for the fact that mature, open, positive interactions and structure in the families of hemodialysis patients are correlated with adherence to the treatment regimen and a relatively positive medical assessment.

Pentecost (1970) and Pentecost, Zwerens, and Manuel (1976) investigated intra-family communication, and focused on the explicitness of each family member's verbal statements and the manner of taking responsibility for one's own statements. It was found that family attitudes, specifically the ability to express one's personal identity and to have it accepted by the rest of the family, was associated with adjustment to hemodialysis. Many families, however, react in a maladjusted manner. Mass and De-Nour (1975) found that in the seven families of their sample who allowed themselves to be interviewed, there was a striking lack of empathy as well as hostility between the parents while they manifested a great deal of hostility against the human environment--medical staff, friends, extended family--and suppressed the expression of empathy in the children.

Some work has been done in the area of assessing the marriage relationships of hemodialysis patients, with most of the effort being focused on the sexual relationship (Abram et al., 1975; Levy, 1973, 1974; Steele et al., 1976). Information on other aspects of the relationship, however, appears to be sparse. Finkelstein, Finkelstein, and Steele (1976) used a marital questionnaire on 17 stable dialysis patients and their spouses. They found 9 of the 17 couples reported multiple areas of serious marital conflict comparable

to that found in patients seeking marital counseling, and the authors interpreted this as severe marital discord. Yet when the patients were asked for a global assessment of their marriages, 88% of the couples rated their marital problems as of minor importance and their marriages as basically satisfactory. In another report this same group of researchers (Steele et al., 1976) found no correlation between marital discord and the patient's depression or problems with intercourse.

In a study of satisfaction with family life, Friedman, Goodwin, and Chaudhry (1970) found that only 5 of 13 spouses felt family life had been worthwhile since hemodialysis began, but the majority felt that the relationship with the patient was closer and better than before. Holcomb and MacDonald (1973) found that 87% of the spouses in their sample said they enjoyed family life, even though many of them showed many psychopathological reactions. Czaczkes and De-Nour (1978) explain such apparently contradictory findings as being the result of the use of denial and reaction formation while the spouse's basic attitude toward the patient is extremely negative and hostile. Furthermore, Short and Wilson (1969) contend that a family which continually denies the impact of its hemodialysis problems cannot function effectively. Steele et al. (1976) explain the apparent contradictions by suggesting that for hemodialysis families,

the medical problems eclipse the other family problems that normally would have led to the seeking of professional help or separation.

There is little information on the reaction of the children of hemodialysis patients, and what is available is contradictory. For example, whereas Friedman et al. (1970) found that there was no great impact on children, Tsaltas (1976) reported that all 15 of the children of home dialysis patients in her sample showed depressive and hypochondriacal MMPI profiles and severe disturbances in their human figure drawings. Mass and De-Nour (1975) found that children of center dialysis patients were often ashamed of their parent's illness.

Prediction of Adjustment

Predicting prospective patients' adjustment to hemodialysis has been a goal of medical staffs ever since the inception of this treatment modality. This was especially important in the early years of the sixties when staffs were seeking some valid method of patient selection for the few machines which were available, but the interest in prediction continues to the present in order to anticipate patients who may need psychological intervention at some point.

Some of the work done in this general area has focused on the correlates of survival as a way of singling out factors which may be related to adjustment, but with contradictory

results (Cummings, 1970; Eisendrath, 1969; Farmer, Bewick, Parsons, & Snowden, 1979; Foster, Cohn, & McKegney, 1973; Glassman & Siegel, 1970). De-Nour and Czaczkes (1976) used predialysis interviews with 136 patients and reinterviewed them at various points during the following three years. They found that it was possible to predict, at a highly significant statistical level, the three major aspects of adjustment: namely, compliance with the diet, vocational rehabilitation, and psychological condition. They note that there was a slight tendency to overestimate patients' adjustment potential, and suggest that psychological intervention to help the staff develop a realistic attitude and to help reduce physician's denial can contribute to enabling patients to fulfill their adjustment potential.

One of the first studies of a prospective nature was that of Sand, Livingston, and Wright (1966) with a small homogeneous group of patients who had no severe psychopathology to begin with. They found the following characteristics to be empirically related to adjustment: (1) somewhat higher intelligence; (2) less defensive attitude about admitting to anxiety or emotional difficulty; (3) relative prominence of depression over somaticizing defenses during the pretreatment period; and (4) satisfactory emotional support from members of the family. They also found that past experiences with illness was important

to adjustment. Contrary to the finding of De-Nour and Czaczkes (1976), they found that the largest number of errors in prediction arose from predicting "adequate" adjustment for patients who actually came to show "superior" adjustment.

In a relatively recent study of many of the same factors as those explored by Sand et al. (1966), Greenberg, Weltz, Spitz, and Bizzozero (1975) could not find enough evidence to confirm that above average intelligence, willingness to discuss emotional difficulty and anxiety openly, or relative prominence of depression over somaticizing defenses in the pretreatment period could be used as valid criteria for predicting patient adjustment. However, their sample was very small ($n=7$). They did find that stability, maturity, and a professed willingness to cooperate were valid criteria.

The most ambitious and systematic prospective study of adjustment has been undertaken by Malmquist and her colleagues in Sweden (Hagberg, 1974; Hagberg & Malmquist, 1974; Malmquist, 1973a, 1973b; Malmquist & Hagberg, 1974; Malmquist, Kopfstein, Frank, Picklesimer, Clements, Ginn, & Cromwell, 1972). In an initial study with a small sample, Malmquist et al. (1972) found a perfect correlation between good adjustment and closeness to mother as an adult. Other variables significantly correlated with good adjustment were the lack of irritability and reported anxiety, adaptability to previous life changes,

and the lack of a focal dependence on one parent (versus on both parents) as a child. These results are congruent with Viederman's (1974) finding that patients make an adaptive, limited regression if they had a gratifying infantile mutuality with their mothers which engendered a deep sense of confidence, basic trust, and hope which persists in the face of great frustration and danger. Similarly, Oberley and Oberley (1975) contend that predialysis strengths, weaknesses, and modes of coping are highlighted by the dialysis experience and thus can be useful in predicting adjustment.

In a prospective study that continued Malmquist's work by investigating the predictive value of intelligence, cognitive deficit, and ego defense structures, Hagberg (1974) found that although higher general intelligence and fewer marked signs of organicity prior to dialysis led to more rapid adjustment to the treatment situation, these factors had no predictive value after 12 months of dialysis. An habitual disposition to react with flexibly repressive defensive style seemed to promote early adaptation, while an habitual disposition to basically use isolation had a negative prognostic value over the long-term course of treatment.

In summarizing the prospective work of Malmquist and her colleagues, Hagberg and Malmquist (1974) conclude that in

addition to the factors mentioned previously, the following are basic prognostic indicators of rehabilitation: ability for positive identification, regular social contacts, "adequate" reaction to kidney disease, and expectation of fast rehabilitation.

Several prospective studies have sought to use the MMPI as a predictive tool. Freedman, Sherrad, Calsyn, and Paige (1980) found profile differences between 107 dialysis patients who had a good, fair, or poor vocational rehabilitation. Marshall, Rice, O'Mera, and Shelp (1975) used the MMPI with patients in home dialysis training to form a group of "identifiers" who had their highest scale on one of the first three, indicating an internalizing or somaticizing psychological response, and "antagonizers" whose highest scale was on 4, 6, or 9. The results indicated that antagonizers do better in terms of completing training--which suggests that some manifestation of anger is good--while the two groups did not differ significantly in degree of overall inferred psychopathology. They also found that age plus classification as identifier or antagonist was a better predictor of success in training than either variable alone.

Ziarnik, Freeman, Sherrard, and Calsyn (1977) used the MMPI to compare mortality rates. The group of patients who died within one year of initiating dialysis was characterized

by feelings of helplessness and high levels of depression, anxiety, and preoccupation with somatic difficulties. Malmquist et al. (1972) found the psychasthenia scale of the MMPI (#7) to be significantly correlated with adjustment.

Summary

To conclude, then, it seems that four major factor clusters are closely related to the issue of dietary compliance in hemodialysis: medical factors, intrapsychic factors, family and marital factors, and life engagement factors. Figure 1 illustrates the important explanatory factors thought to be related to the investigated phenomenon. Factors marked by an asterisk represent variables this study will attempt to investigate further.

Although this study is not designed to test any control theory, it is posited that the notion of control as expressed in control theories described earlier (Carver & Scheier, 1972; Thompson, 1981) offers an overall theoretical framework to the understanding of compliance. The whole experience of hemodialysis entails an objective medical loss of control over significant bodily functions, as well as a derivate loss of control over lifestyle, mobility, and general wellness. However, while the patients can do little to regain control of their kidneys, there are still numerous aspects of their lives they can control, the dietary medical regimen

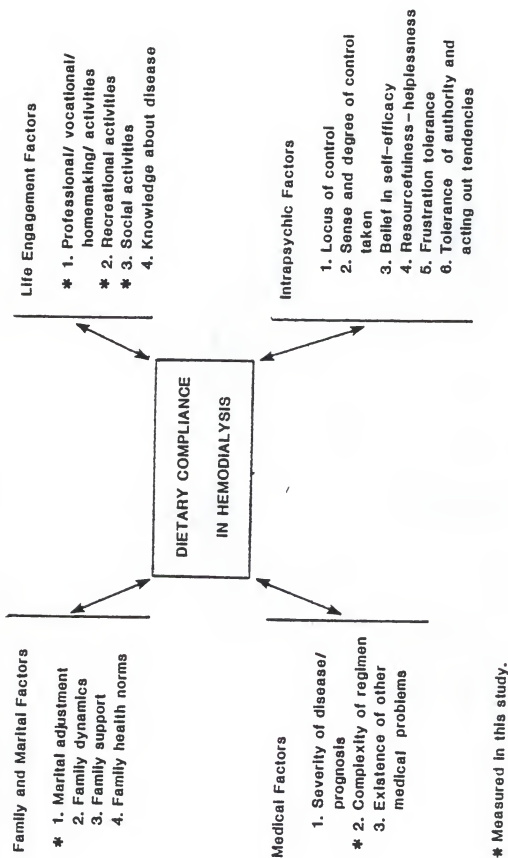


Figure 1

Factors related to dietary compliance in hemodialysis

being just one. It is suggested that those patients who demonstrate an active engagement in life, as expressed, for example, in the active engagement in marital, social, recreational, and vocational behaviors, will also tend to be those who have assumed control over their disease (by adherence to dietary regimen). These are the people who will probably experience the diet and treatment as less stressful (Bowers, 1968; Geer et al., 1970; Szpiller & Epstein, 1976; Wortman, 1975). Those who do not let their marriages deteriorate under the stresses of hemodialysis, those who actively shape, modify, and interact with their environments make their lives more predictable (Miller, 1979), enhance their self-image (de Charms, 1968), and minimize the dangerous or unpleasant consequences of lack of action (Lefcourt, 1973). It is, thus, hypothesized that higher degrees of compliance will be found among those who are more fully and pleasurably interacting with their environments and thus having a more effective control of their lives.

Operationally speaking, it is anticipated that

1. Patients who would be reported to be actively engaged in vocational, recreational, and/or social activities (life engagement) would also tend to comply better with the dietary medical regimen.

2. There would be a positive significant relationship between the degree of marital adjustment, as perceived by the spouse, and the level of medical compliance.

CHAPTER III METHOD

Subjects

Participants in this study were 69 spouses of hemodialysis patients who volunteered to fill out the research questionnaire. The patients themselves did not participate directly in this study, as will be explained in the Procedure section.

Subjects were recruited from five hemodialysis clinics: three in North Central Florida, one in Mobile, Alabama, and one in New York. Data were collected in the period of March-May, 1984.

Seventy-two percent of the patients were males, 28 percent were females. Fifty-two percent of the patients were Caucasians, while blacks were 42 percent of the sample.

Patients were between 6 and 180 months on dialysis ($M=43$, $S.D.=31$). Their ages varied between 30 and 79 ($M=59$, $S.D.=11$).

Although some of the subjects have had some college education, most of them have not completed high school. The average level of patient education was 9 years ($S.D.=4$) ranging from 0 to 17.

Instrumentation

Two paper and pencil instruments were used in this study.

The Short-Form Locke Marital Adjustment Questionnaire (LMQ)

The short-form Locke Marital Adjustment Questionnaire (Locke, 1951) was used to assess the patient's marital adjustment (Kimmel & Van Der Veen, 1974), as perceived by the patient's spouse. It was assumed that the spouses' perception of the marriage is determined by the patients' conduct and is related, as will be shown later, to the patients' marital adjustment.

The original questionnaire was constructed in a landmark study of marital adjustment by Locke (1951). In his study scores for each subject were secured by adding together the weights assigned the given answers to 29 adjustment items. Weights were determined by the degree of differences between the percentages of happily married and divorced giving the various answers to each question. For example, one of the questions was: "Do husband and wife engage in outside activities together?" There were four possible answers. These answers, the percentage of happily married and divorced subjects for each answer, and the assigned weights were as follows:

Answer	Married (%)	Divorced (%)	Weight Assigned
All	47.2	23.3	5
Some	45.6	43.7	4
Very Few	5.1	26.2	2
None	2.1	6.8	2

The weight to each answer or category of a question was assigned by the method of graphical determination of weights, or an abac constructed by J.P. Guilford (1950). The original test was composed of 29 items. It included 19 items from the Burgess-Cottrell marital adjustment test (Burgess & Cottrell, 1939), two adaptations from Terman's items (Terman, 1938), and eight which were formulated by Locke. Although there was considerable overlap between the answers of men and women, there was a slight difference. Consequently, some of the weights assigned to the items were slightly different. The significant difference ($p < .01$) reported by Locke (1951), between the average scores of the divorced and the married indicate that the two criteria have a satisfying validity, in that they separate the well-adjusted from the poorly adjusted.

When marital adjustment scores derived from LMQ were compared to the scores derived from the 26 Burgess-Cottrell questions and their weights, high correlations were found. The correlations were as follows: .85 married men, .83 divorced men, .88 married women, and .87 divorced women (Locke, 1951).

How much correspondence is there between the adjustment scores of husbands and their respective wives? The first answer to this question was given by Burgess and Cottrell (1939)

and was strong affirmative ($r=.88$). Terman (1938) gave an affirmative but by a considerably less emphatic answer ($r=.59$). Locke's (1951) answer was somewhat affirmative in the case of happily married spouses ($r=.36$), but negative in the case of divorced spouses ($r=.04$). Harter (1950), too, gave affirmative response for married spouses ($r=.65$). When using a marital adjustment assessment by one spouse, it is important to note that although the obtained scores would probably not totally correspond to those of the other spouse, they would be much closer together than the scores of divorced spouses and would reflect that one spouse's perception of the marriage. The happiness of the patients' spouses was not only regarded in this study as being closely related to the patients' own marital happiness, but also as having an impact on the patients and their readiness to comply with a demanding medical regimen.

In 1974, Kimmel and Van Der Veen reexamined factors discovered in a study conducted by Locke and Williamson (1958). Kimmel and Van Der Veen's study was based on all 23 items which were found to be significant in the original Locke (1951) study, it analyzed husband and wife scores separately and it employed a statistical criterion for the number of factors to be retained and stated. Principal axis factor analysis with varimax rotations of data for 149 wives and 157 husbands indicated that

the instrument is an internally consistent measure of marital adjustment and that this general aspect consists of two separate components--sexual congeniality and compatibility. The separate analyses for both husband and wives showed that there are both distinctive differences between the factor patterns of husbands and wives, as well as considerable overlap between them.

The questionnaire (see Appendix B) consists of the 23 items proposed by Locke (1951). Twelve of the items have multiple-choice responses, nine items ask the extent of agreement or disagreement on marital issues. Responses to these items are checked on a 6-point scale from "always agree" to "always disagree." One item, number of "serious difficulties," consists of 22 areas of difficulty of which the respondent checks as many as apply. The last item provides a 7-point scale from "very unhappy" to "perfectly happy" and the instructions: "on the scale line below check the mark which best describes the degree of happiness, everything considered, of your marriage. . . ."

Responses were scored according to a system of weighted scores (Kimmel & Van Der Veen, 1974) which followed very closely, but not exactly, the original scoring procedure described by Locke (1951). The total score consisting of the sum of all the scores on all the items has a possible range of 48 to 138 for husbands and 50 to 138 for wives. The normal means and standard deviations of the total score on the marital

Adjustment Questionnaire are 110.22 and 16.29 for husbands, and 108.40 and 16.32 for wives (Kimmel & Van Der Veen, 1974).

Demographic and Life Engagement Questionnaire

The Demographic and Life Engagement Questionnaire (see Appendix C) is a data sheet developed by the researcher to assess demographic characteristics of the sample of hemodialysis patients to be studied, as well as their engagement in various activities. The use of this questionnaire allowed the investigator to assess the sex, ethnic origin, and age of patients, the patient's level of education, and the number of months on dialysis. The second area of inquiry addressed the level of the patient's active engagement in various spheres of life. The questionnaire has allowed the researcher to assess the total number of weekly hours the patient typically engaged in such activities as professional/vocational, household/homemaking, recreational and social. A final area of inquiry was assessing the number of different medications the patient is required to take, as an indicator of the complexity of the medical regimen. This data was collected from two sources: the patient's nurse and the spouse.

Research Design

This study employed a correlational research design. Data was collected to determine whether, and to what degree, relationships exist between marital adjustment and life

engagement factors and two measures of compliance. The dependent variables for this study were predialysis blood potassium level and weight gain as measures of dietary compliance (De-Nour & Czaczkes, 1972).

The data for the independent variables were collected from the patients' spouses. Three major independent variables were studied: (1) spouse marital adjustment, (2) number of medications taken by the patients, and (3) degree of life engagement as measured by spouse estimation of number of hours of patient engagement in different activities.

Null Hypotheses

The following hypotheses, stated in null form, were tested in this study:

Hypothesis 1: There is no global relationship between the groups of dependent and independent variables.

Hypothesis 2: There is no relationship between any of the independent variables and any of the measures of dietary compliance.

Hypothesis 3: There is no relationship between the group of independent variables and any of the measures of dietary compliance.

Procedure

Married hemodialysis patients were recruited by an in-house professional contact person, who had been informed about the study and its purposes, and had agreed to serve as a liason between the researcher and the target population.

After written endorsements of heads of clinics were secured, the liasons, mostly nurses and social workers, were all briefed by the researcher to ensure optimal standardization of procedures. All spouses who agreed to participate in this study were asked to sign a consent form indicating their volunteer participation (Appendix A).

Questionnaires were directly handed to spouses and patients, with the instruction to return them on their next treatment appointment.

All spouses were briefed by the liasons, either face-to-face, or by phone. They were told that participation in this national study is highly encouraged by the medical director of the clinic and that this study might help find some new ways of improving patient compliance with the dietary medical regimen. They were also encouraged to seek the liason's assistance in filling out the questionnaire or in case questions arose. Only 4 out of the 69 participants in this study indicated they would need assistance with the quesitonnaire. To these, the instructions and questions were read, ensuring the participants' privacy while marking the relevant answers.

After the completed questionnaires had been returned, the liaisons retrieved the patients' bio-medical data from the previous three months, and enclosed them with the corresponding research questionnaires. The complete data packages were not returned to the investigator before all patient and spouse names were deleted to ensure patient-physician confidentiality.

CHAPTER IV RESULTS

The first null hypothesis of this study states that there is no relationship between the group of independent variables and the group of dependent variables. The independent variables in the current study were marital adjustment, education, measures of life engagement, the amount of time on dialysis (TOD), and the complexity of the medical regimen; the dependent variables were measures of medical dietary compliance.

Tables 1, 2, and 3 present the canonical correlations between the linear combination of the independent variables and the linear combination of the dependent variables, the standardized canonical coefficients, and the canonical structure, respectively. The squared canonical correlation is .58. This statistic is significant using the F transformation of Wilk's Lambda, $F(18,76) = 3.536$, $p < .0001$.

Among the independent variables, those which seem most strongly related to the independent canonical factor are the marital adjustment score (LMQ), age, and MEDO (number of medications taken by patient, as indicated by nurse). Of the dependent variables, inter-dialysis weight gain (W), appears to be very strongly related to the dependent canonical factor, while potassium (K) level is unrelated to it.

Table 1
Canonical Correlation Analysis

Canonical Correlations and Tests of Null Hypothesis 1									
Canonical Correlation	Adjusted Can. Corr.	Approximate Std. Error	Variance Ratio	Canonical R-Square	Likelihood Ratio	F	Num DF	Den DF	Prob > F
0.758	0.680	0.061	1.356	0.575	0.296	3.536	18	76	0.0001
Multivariate Test Statistics and F Approximations									
Statistic	Value	F	Num DF	Den DF	Prob>F				
Wilk's Lambda	0.296	3.536	18	76	.00006				
Pillai's Trace	0.877	3.389	18	78	.00009				
Hotelling-Lawley Trace	1.789	3.678	18	74	.00004				
Roy's Greatest Root	1.356	5.878	9	39	.00004				
Raw Canonical Coefficients for the Variables									
Variable	V ₁		W ₁						
Independent Variables									
EDUC	-.022								
TOD	-.006								
VOC	0.019								
REC	-.071								
SOC	-.155								
AGE	-.044								
MEMO	0.242								
MEMDIF	-.174								
LMQ	-.034								
Dependent Variables									
K	0.319								
W	0.558								

Table 2
Canonical Correlation Analysis

Standardized Canonical Coefficients for the Independent Variables

Variable	V_1
EDUC	-0.098
TOD	-0.197
VOC	0.250
REC	-0.310
SOC	-0.480
AGE	-0.519
MEDO	0.482
MEDDIF	-0.228
LMQ	-0.619

Standardized Canonical Coefficients for the Dependent Variables

Variable	W_1
K	0.196
W	1.007

Table 3
Canonical Variable

Correlations Between the Independent Variables and their Canonical Variable	
Variable	V_1
EDUC	0.047
TOD	0.145
VOC	0.219
REC	-0.198
SOC	-0.245
AGE	-0.444
MEDO	0.310
MEDDIF	-0.382
LMQ	0.533
Correlations Between the Dependent Variables and their Canonical Variable	
Variable	W_1
K	0.062
W	0.980
Correlations Between the Independent Variables and the Canonical Variable of the Dependent Variables	
Variable	W_1
EDUC	0.035
TOD	0.110
VOC	0.166
REC	-0.150
SOC	-0.186
AGE	-0.337
MEDO	0.235
MEDDIF	-0.290
LMQ	-0.404
Correlations Between the Dependent Variables and the Canonical Variable of the Independent Variables	
Variable	V_1
K	0.047
W	0.744

The second null hypothesis states that there is no relationship between any of the independent variables and any of the measures of dietary compliance. Table 4 presents the correlation coefficients of all the possible relationships between the independent variables.

It should be noted that MEDDIF represents the difference between the spouse's estimate of the number of different medications taken by the patient (MEDS), and the actual number of medications taken by the patient, as indicated by his or her nurse (MEDO). It should also be noted that three of the measures presented in Table 4 are linear representations of other variables. ACTIV is the sum total of the weekly hours the patient engaged in vocational (VOC), social (SOC), and recreational (REC) activities. Two overall compliance measures are introduced. COMP is an overall compliance measure and is composed of two scores: the average pre-dialysis potassium (K) level of the patient over the last three months, plus the mean inter-dialysis fluid weight gain (W) over the same period of time. COMP2 is a weighted overall compliance measure. In this case, K and W were each multiplied by the approximation to their optimal weights, as indicated by the canonical correlation analysis. Thus, $COMP2 = .32K + .56W$. It should be noted that the higher the K, W, COMP, or COMP2 scores are, the less compliant the patient is of his/her dietary regimen. Six

Table 4
Correlations Between Dependent and Independent Variables

Independent Variables	Dependent Variables			
	K	W	COMP	COMP2
AGE	-0.030	-0.233	-0.223	-0.230
EDUC	-0.050	-0.033	-0.046	-0.041
TOD	0.008	0.163	0.153	0.159
MEDO	-0.108	0.238	0.197	0.218
MEDS	-0.106	0.261*	0.208	0.232
MEDDIF	0.080	-0.304*	-0.273	-0.290
VOC	0.120	0.163	0.186	0.178
SOC	-0.009	-0.000	-0.002	-0.001
REC	-0.261*	-0.122	-0.190	-0.164
ACTIV	0.019	0.095	0.093	0.095
LMQ	0.080	-0.394***	-0.338**	-0.365**

* $p < .05$

** $p < .01$

*** $p < .001$

correlations were found to be significant. The marital adjustment score was negatively related to three measures of dietary abuse.

A negative correlation of .4 was found between weight gain, the highly loaded single compliance variable, and marital adjustment score. Pre-dialysis potassium (K) level was negatively related to the number of weekly hours the patient has been perceived to be engaged in recreational activities (REC).

A negative correlation was noted between MEDDIF and the inter-dialysis fluid weight gain (W). It seems, then, that spouses' overestimation of the number of different medications taken by the patient (negative, or very low MEDDIF) was related to higher levels of fluid abuse. Conversely, underestimation of the number of different medications taken (higher MEDDIF) was related to better patient compliance (low W). A related finding indicates a negative relationship between the perceived amount of different medications taken by the patient (MEDS) and the inter-dialysis fluid weight gain (W).

Though not significant, a positive relationship trend was observed between age and fluid weight gain.

Six out of the thirty-three Pearson product moment correlations computed were significant at the .05 level. The possibility that these correlations are due to chance was rejected; to obtain a level of confidence above .95 that this was not a

chance finding, it would have been sufficient to find two significant correlations. The second null hypothesis was, thus rejected.

The third null hypothesis states that there is no relationship between the group of independent variables and any of the dependent variables. Table 5 presents the statistics of the regression analysis of the relationship between K and the independent variables. Since MEDDIF is a linear combination of MEDS and MEDO, one of the three variables could not be included in the calculation. Table 4 indicated that MEDS and MEDDIF have a slightly higher correlation with the dependent variables than MEDO. MEDO was, therefore, not included in the calculation.

Although $R=.58$, the proportion of the total variance accounted for by the relationship between (K) and the independent variables was only 30.3 percent. The correlation was not significant, $F(9, 39)=1.885$, $p<.083$.

Table 6 presents the regression analysis' statistics for the relationship between W and the independent variables. It can be seen that this was a much stronger relationship, $R=.752$, $F(9, 39)=5.636$, $p<.0001$.

Table 7 presents the statistics of the regression analysis for the relationship between COMP and the independent variables; a significant correlation was found, $R=.755$, $F(9, 39)=5.746$, $p<.0001$. It seems that the addition of K to W to form

Table 5
Regression Analysis for the Relationship Between K
and the Independent Variables

Source	DF	SS	MS	F	Prob>F
Model	9	5.46	0.607	1.885	0.083
Error	39	12.57	0.322		
C Total	48	18.04			

Root MSE	Dep. Mean	C.V.	R	R-Square	Adj. R-Sq.
0.567	4.971	11.420	0.575	0.303	0.142

Variable	DF	Parameter Estimate	Standard Error	T	Prob > T
INTERCEP	1	6.080	1.050	5.786	0.0001
AGE	1	-0.016	0.010	-1.595	0.119
EDUC	1	0.0005	0.022	0.024	0.980
TOD	1	-0.005	0.003	-1.382	0.175
MEDS	1	-0.011	0.051	-0.224	0.820
MEDDIF	1	0.064	0.081	0.792	0.430
VOC	1	-0.004	0.008	-0.493	0.625
SOC	1	0.019	0.029	0.667	0.510
REC	1	-0.083	0.022	-3.713	0.0006
LMQ	1	0.003	0.005	0.711	0.480

Table 6
Regression Analysis for the Relationship Between W
and the Independent Variables

Source	DF	SS	MS	F	Prob>F
Model	9	88.349	9.816	5.636	0.0001
Error	39	67.930	1.741		
C Total	48	156.280			

Root MSE	Dep. Mean	C.V.	R	R-Square	Adj. R-Sq.
1.319	4.400	29.99	0.752	0.565	0.465

Variable	DF	Parameter Estimate	Standard Error	T	Prob> T
INTERCEP	1	11.848	2.442	4.851	0.0001
AGE	1	-0.051	0.023	-2.190	0.035
EDUC	1	-0.031	0.052	-0.600	0.55
TOD	1	-0.006	0.008	-0.776	0.44
MEDS	1	0.335	0.119	2.810	0.008
MEDDIF	1	0.055	0.188	0.295	0.77
VOC	1	0.029	0.020	1.404	0.17
SOC	1	-0.222	0.068	-3.265	0.002
REC	1	-0.048	0.052	-0.929	0.36
LMQ	1	-0.049	0.011	-4.212	0.0001

Table 7
Regression Analysis for the Relationship Between COMP
and the Independent Variables

Source	DF	SS	MS	F	Prob>F
Model	9	91.323	10.147	5.746	0.0001
Error	39	68.876	1.766		
C Total	48	160.200			

Root MSE	Dep. Mean	C.V.	R	R-Square	Adj. R-Sq.
1.328	9.371	14.18	0.755	0.570	0.470

Variable	DF	Parameter Estimate	Standard Error	T	Prob> T
INTERCEP	1	17.929	2.459	7.289	0.0001
AGE	1	-0.067	0.023	-2.857	0.007
EDUC	1	-0.030	0.052	-0.586	0.56
TOD	1	-0.011	0.008	-1.361	0.18
MEDS	1	0.324	0.120	2.694	0.01
MEDDIF	1	0.119	0.190	0.631	0.53
VOC	1	0.024	0.021	1.184	0.24
SOC	1	-0.203	0.069	-2.958	0.005
REC	1	-0.132	0.052	-2.509	0.016
LMQ	1	-0.045	0.011	-3.879	0.0004

the overall compliance measure neither increased the total variance accounted for, nor substantially changed the structure of the regression.

Table 8 presents the multiple correlation between COMP2 and the independent variables. This correlation was also significant, $R=.760$, $F(9, 39)=5.878$, $p<.0001$. When compared to the relationship between W alone, and the independent variables, this regression resulted in an increase of 1 percent to the total variance accounted for.

All the regression analyses performed to determine the relationships between the individual dependent variables and the group of independent variables were found to be potent and significant, except for the one between K and the independent variables. The third research hypothesis was substantially supported. Stepwise regression analyses at .15 and .10 significance levels for entry were computed and are presented in Appendix E.

Table 9 presents some descriptive statistics of the research variables. While the mean LMQ score for a normal sample is 109.3, $SD=16.3$ (Kimmel & Van Der Veen, 1974), the current sample is somewhat lower ($\bar{x}=106.5$, $SD=16.8$). On the average, the current sample falls within what is widely

Table 8
Regression Analysis for the Relationship Between COMP2
and the Independent Variables

Source	DF	SS	MS	F	Prob>F
Model	9	27.819	3.09	5.878	0.0001
Error	39	20.507	0.52		
C Total	48	48.326			

Root MSE	Dep. Mean	C.V.	R	R-Square	Adj. R-Sq.
0.725	4.054	17.883	0.76	0.576	0.478

Variable	DF	Parameter Estimate	Standard Error	T	Prob > T
INTERCEP	1	8.581	1.342	6.394	0.0001
AGE	1	-0.033	0.012	-2.632	0.014
EDUC	1	-0.017	0.028	-0.605	0.55
TOD	1	-0.005	0.004	-1.137	0.26
MEDS	1	0.184	0.066	2.807	0.008
MEDDIF	1	0.051	0.103	0.499	0.62
VOC	1	0.014	0.011	1.308	0.199
SOC	1	-0.118	0.037	-3.161	0.003
REC	1	-0.054	0.028	-1.877	0.07
LMQ	1	-0.026	0.006	-4.114	0.0002

Table 9
Descriptive Statistics of the Research Variables

Variable	N	Mean	Standard Deviation	Range
AGE	69	59.347	11.419	30 - 79
EDUC	69	9.362	3.757	0 - 17
TOD	69	42.753	30.964	6 - 180
MEDO	51	5.745	1.957	3 - 10
MEDS	64	6.078	2.950	2 - 15
MEDDIF	49	-0.061	1.313	-3 - 3
VOC	68	8.602	11.719	0 - 40
SOC	68	2.632	4.167	0 - 20
REC	68	2.955	4.180	0 - 20
ACTIV	68	14.191	14.621	0 - 45
LMQ	69	106.492	16.769	72 - 135
K	69	5.010	0.601	4 - 6.5
W	69	4.518	1.849	1.4 - 9.2
COMP	69	9.528	2.009	5.9 - 15.3
COMP2	69	4.133	1.074	2.296 - 7.10

considered an acceptable range of pre-dialysis potassium levels (3.3-5.3), as well as within an acceptable range for inter-dialysis fluid weight gain (1.5-5.5 lbs.).

Table 10 presents the Pearson correlations among the independent variables. Several significant correlations were found. AGE was negatively related to the variables EDUC, VOC, REC and ACTIV. The older patients seem to be less educated and less active. EDUC was positively related to REC and MEDO. TOD was positively related to MEDO and MEDS, but negatively related to VOC, REC, and ACTIV. MEDO was highly related to MEDS and negatively related to VOC. MEDS was found to be negatively related to MEDDIF, VOC, and ACTIV.

It is evident that the major research variables are quite independent of each other. All the relationships among VOC, SOC, and REC were not significant, except for a low positive relationship between VOC and SOC. LMQ is not related to any other independent variable.

The correlation between the two measures of compliance, K and W, was low and nonsignificant, $r(67) = .11$, $p < .35$.

Table 11 presents the breakdown of the descriptive statistics for males, females, blacks, and whites. Some of the more striking differences were observed when white

Table 10
Correlations Among the Independent Variables

Independent Variables	Independent Variables				
	AGE	EDUC	TOD	MEDO	MEDS
AGE	1.000				
EDUC	-0.363**	1.000			
TOD	0.046	0.030	1.000		
MEDO	-0.098	0.322*	0.450***	1.000	
MEDS	0.112	0.101	0.389**	0.826 ⁺	1.000
MEDDIF	0.100	0.042	-0.027	0.050	-0.520 ⁺
VOC	-0.564 ⁺	0.165	-0.242*	-0.227	-0.394**
SOC	-0.191	-0.019	-0.077	0.064	0.053
REC	-0.240*	0.253*	-0.265*	0.061	-0.165
ACTIV	-0.576 ⁺	0.199	-0.292*	-0.150	-0.360**
LMQ	0.008	0.165	-0.116	-0.102	-0.066

*p<.05

**p<.01

***p<.001

+p<.0001

Table 10--extended

MEDDIF	VOC	SOC	REC	ACTIV	LMQ
1.000					
0.205	1.000				
0.052	0.109	1.000			
0.105	0.273*	0.118	1.000		
0.213	0.910 ⁺	0.406***	0.539 ⁺	1.000	
0.195	0.119	-0.039	0.086	0.109	1.000

Table 11
Descriptive Statistics of the Research Variables for
Male, Female, White, and Black Patients

Males				
Variable	N	Mean	Standard Deviation	Range
AGE	50	59.32	11.782	30 - 79
EDUC	50	8.80	3.979	0 - 14
TOD	50	41.72	27.994	6 - 116
MEDS	46	6.43	3.166	2 - 15
VOC	50	7.24	10.389	0 - 36
REC	50	2.32	3.241	0 - 12
SOC	50	3.20	4.659	0 - 20
LMQ	50	106.64	16.864	72 - 135
K	50	4.96	0.566	4 - 6
W	50	4.48	1.904	1.4 - 9.2
MEDO	36	5.72	2.185	3 - 10
MEDDIF	34	-0.24	1.232	-3 - 2
COMP	50	9.44	2.085	5.9 - 15.3
ACTIV	50	12.76	13.258	0 - 44

Females				
Variable	N	Mean	Standard Deviation	Range
AGE	19	59.42	39.00	39 - 75
EDUC	19	10.84	8.00	8 - 17
TOD	19	45.47	7.00	7 - 180
MEDS	18	5.17	3.00	3 - 10
VOC	18	12.39	0.00	0 - 40
REC	18	4.72	0.00	0 - 20
SOC	18	1.06	0.00	0 - 5
LMQ	19	106.10	77.00	77 - 128
K	19	5.13	4.10	4.1 - 6.5
W	19	4.63	1.40	1.4 - 7
MEDO	15	5.80	4.00	4 - 8
MEDDIF	15	0.33	-2.00	-2 - 3
COMP	19	9.76	6.50	6.5 - 11.9
ACTIV	18	18.17	0.00	0 - 45

Table 11--continued

Whites				
Variable	N	Mean	Standard Deviation	Range
AGE	40	58.48	11.340	30 - 75
EDUC	40	10.50	3.508	0 - 17
TOD	40	45.02	26.891	6 - 116
MEDS	38	6.32	3.005	3 - 15
VOC	40	11.40	13.551	0 - 40
REC	40	3.92	4.665	0 - 20
SOC	40	2.72	3.210	0 - 10
LMQ	40	110.48	19.227	72 - 135
K	40	5.04	0.706	4 - 6.5
W	40	4.35	2.095	1.4 - 9.2
MEDO	28	5.64	1.789	3 - 9
MEDDIF	28	0.07	1.214	-2 - 3
COMP	40	9.38	2.339	5.9 - 15.3
ACTIV	40	18.05	16.073	0 - 45
Blacks				
Variable	N	Mean	Standard Deviation	Range
AGE	29	60.55	11.617	30 - 79
EDUC	29	7.79	3.569	0 - 12
TOD	29	39.62	36.106	6 - 180
MEDS	26	5.73	2.892	2 - 10
VOC	28	4.61	6.887	0 - 21
REC	28	1.57	2.924	0 - 10
SOC	28	2.50	5.308	0 - 20
LMQ	29	101.00	10.683	77 - 117
K	29	4.98	0.425	4.1 - 5.5
W	29	4.75	1.445	2.2 - 7
MEDO	23	5.87	2.180	3 - 10
MEDDIF	21	-0.24	1.445	-3 - 2
COMP	29	9.73	1.453	7 - 12.1
ACTIV	28	8.68	10.187	0 - 30

and black patients were compared. White patients seem to be somewhat more educated, they are much more actively engaged in vocational and recreational activities and appear to be somewhat better adjusted in marriage. When males were compared to females (races combined), the former appeared to be more active than the latter.

In order to test for significant differences due to race and sex or the interaction between them two-way analyses of variances were performed. The source tables for the variables that had significant effects are found in Appendix E.

A significant interaction between race and sex was observed when time on dialysis (TOD) was the dependent variable ($F(3, 65)=5.47, p<.05$). It seems the effect is due to the fact that white males were longer on dialysis ($F(1)=4.05, p<.05$). A seemingly larger difference between black and white females was not significant because of the small number of black females in this sample ($N=7$).

When marital adjustment was the dependent variable a significant race effect was found ($F(1)=10.9, p<.001$). Blacks scored lower on the marital adjustment scale ($\overline{LMQ}=101$) than whites ($\overline{LMQ}=110.5$). The interaction between race and sex (see figure 2) was also significant ($F(1)=5.63, p<.05$). A further

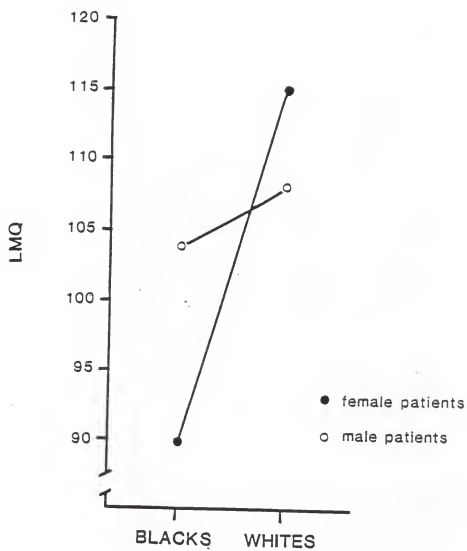


Figure 2
Marital adjustment (LMQ) by race and sex

analysis for the source of that interaction indicated that black male spouses (who filled out the questionnaires relating to the black female patients) seem to differ most by scoring significantly less on the LMQ (90) than white male spouses (115) ($F(1)=18.82$, $p<.0004$).

Figure 3 describes the interaction between race and sex when pre-dialysis potassium (K) level is the dependent variable. This significant interaction ($F(3,65)=8.40$, $p<.005$) was primarily a result of the fact that black females were significantly more compliant (lower K) than white females, in terms of high potassium food ($F(1)=6.46$, $p<.05$).

The difference between the number of weekly hours blacks and whites typically engaged in vocational activities has also been found to be significant ($F(1)=7.15$, $p<.001$). White patients reportedly spent more time in vocational activities than black patients did.

A significant race effect was found when the overall activity score (ACTIV) was the dependent variable ($F(1)=8.07$, $p<.005$). Interestingly, although the measures of life engagement were generally found to be related to compliance, black patients on the whole, were not less compliant of their dietary regimen than white patients.

Two other intriguing trends were also noted. White patients tended to spend more hours in recreational activities than black

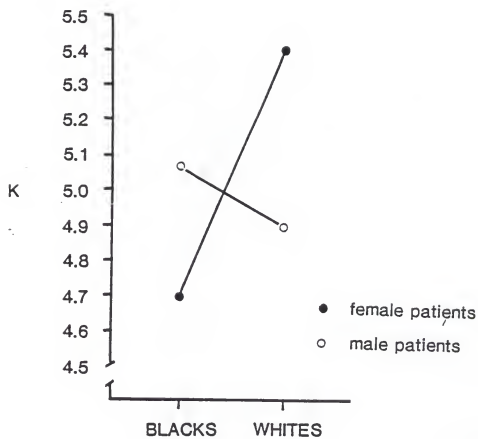


Figure 3

Pre-dialysis potassium level (K) by race and sex

patients ($F(1)=3.48$, $p<.067$). Female patients tended to be less engaged in social activities than their male counterparts ($F(1)=.377$, $p<.057$).

CHAPTER V DISCUSSION

The literature on patient compliance and hemodialysis indicates that in addition to medical and intrapsychic factors, marital and life engagement variables might be related to the investigated phenomenon. The purpose of this study was to determine the relationships between expressions of a self-determining lifestyle (i.e., "life engagement"), the quality of marriage, and measures of patient compliance with the dietary medical regimen.

Summary of the Results

A positive, significant, global relationship was found between the optimal linear combination of the compliance measures and the optimal linear combination of the independent variables: age; years of education; time on dialysis; number of medications taken; weekly hours spent in vocational, recreational, and social activities; and the spouse's marital adjustment score.

Six Pearson correlations between specific dependent and independent variables were found to be significant. The spouse's marital adjustment score was found to be negatively related to the dietary compliance scores except K. In turn, K was found to have a significant negative relationship to the

number of weekly hours spent in recreational activities. The inter-dialysis fluid weight gain (W) was found to be significantly related to the spouse's perception of the number of different medications taken by the patient (MEDS), and negatively related to difference between the objective number of different medications taken by the patient, as indicated by the nurse (MEDO), and MEDS.

Positive, significant relationships were found between the linear combinations of the independent variables and all the measures of dietary compliance except K.

None of the possible relationships among VOC, SOC, and REC were significant, except a low positive relationship between VOC and SOC. The marital adjustment score was not related to any other independent variable. A surprisingly low and nonsignificant relationship was found between K and W.

In addition, the current study revealed that white, male patients were on dialysis longer than black, male patients, that black spouses scored lower on the marital adjustment scale than white spouses, and that the black male spouses scored the lowest.

Black females had significantly lower potassium levels than white females. Black patients were reported to be less actively engaged in vocational activities than white patients; black patients also scored lower on their overall activity measure (ACTIV).

Two noticeable trends were apparent. White patients seem to spend more hours per week in recreational activities than black patients. Female patients seemed to be less engaged in social activities than male patients.

Interpretation of the Results

The results of this study indicate that the phenomenon of patient compliance is best explained by a combination of marital adjustment and life engagement variables, and much better so than by any single independent variable.

The purpose of this study was to gain a better understanding of the costly phenomenon of patient noncompliance with the medical regimen. It was found that the research variables account for almost 60 percent of the total variance of the investigated phenomenon ($R_{\text{CAN CORR}}^2 = .58$).

Later in this section, after the major specific findings have been discussed, a theoretical framework will be presented to integrate the results and explain them.

Not all the obtained results though were expected. Although pre-dialysis potassium level has been used in the past as one indicator of patient compliance (Kaplan De-Nour & Czaczkes, 1972; Yanagida, Streltzer, & Siemsen, 1984), the current study has found that potassium was not an indicator of compliance in the same way as inter-dialysis fluid weight gain. The potassium score was not significantly related to fluid weight gain; it had a very low

canonical factorial load and was only correlated (negatively) to one independent variable (i.e., REC). Even the optimal linear combination of all the research independent variables did not yield a significant correlation. A possible explanation for this phenomenon is that potassium is not a valid measure of food intake compliance for the low SES subjects this study has investigated. Potassium is highly concentrated in bananas, cantaloupes, mushrooms, dates, broccoli and other fresh fruits and vegetables. These foods might be too expensive for the rather poor population to which this sample belongs, or simply not a part of their regular cuisine. In this light, it is suggested that all the reported correlations with K be interpreted with extreme caution.

Among the independent variables, the spouse's marital adjustment score was found to be the single highest correlate of dietary compliance. The LMQ score played a major role in contributing to the general variance accounted for by the research independent variables. This finding is in general agreement with Litman (1974), and Pratt (1976) who have perceived the family as the most important social context in which illness occurs and is dealt with. With the chronic hemodialysis population being an older one, the couple unit is the most relevant family context in hygiene and health care. The findings of this study support the findings of Mathis (1964), and Lynch et al. (1976, 1977) who have shown that negative or upsetting

interactions among family members may have severe negative effects on health and outcome of medical care. An interactive model of understanding the relationship between spouse marital satisfaction and patient compliance appears to be a plausible one.

While it is probably true that unresolved family and marital tensions may not only exacerbate an illness but also undermine patient compliance with the treatment regimen (Chen & Cobb, 1960; Mabry, 1964; Minuchin et al., 1975), one cannot ignore the fact that the family of the chronic hemodialysis patient undergoes significant structural and psychological changes as one family member tries to adjust to the new role of a chronic patient (Huber, 1981; Speidel et al., 1979). In the marital setting the spouses are stressed by multiple losses (e.g., loss of previous sexuality, loss of freedom to travel, etc.) and frustrations that accompany the structural role changes into which they are forced. Many of these role changes involve addition of new responsibilities. Homemakers are forced to become breadwinners; working spouses are often required to take an additional job to compensate for a lost income and increased medical expenses. Breadwinners are required to resume household responsibilities and learn about shopping, cooking and laundry. The most taxing changes of all are probably those involving the couple's interactional patterns. A marked

psychological regression and increased dependency (Shambaugh et al., 1967), and a sharp decline in libido (Abram et al., 1975; Steele et al., 1976) would be a serious challenge to even the most adjusted spouse. Many spouses would be most likely to respond with feelings of deprivation and hostility. Shambaugh et al. (1967) reports that some spouses manifest regressive reactions in the form of serious depression, excessive closeness, denial, and avoidance.

What, then, differentiates the adjusted-compliant couple from the maladjusted-noncompliant one? Steidl et al. (1980) provided evidence for the fact that mature, open, positive interactions and structure in the families of hemodialysis patients are correlated with compliance. Pentecost et al. (1976) found that the ability to express one's personal identity in the family, and to have it accepted by the family, was associated with adjustment to hemodialysis.

A circular process between marital interaction and physical illness seems to offer a satisfactory explanation for the phenomenon. The more mature and satisfying the relationship is, the more freedom the patient has to assert his or her self-identity as somebody other than a hemodialysis patient and the more inclined the patient will be to take control of other facets of his or her life, including the dietary regimen. Conversely the more regressive, passively hostile, and noncompliant the

patient is, the more likely it is for the spouse to become frustrated, distant and disappointed in the relationship.

A possible illustration of this hypothetical bilateral process is found in the negative relationship between MEDDIF (objective number of medications minus spouse perception of that number) and W. It seems that overestimations of the number of medications by spouses is related to higher liquid abuse, while underestimations are related to small interdialysis fluid weight gains. In other words, patient noncompliance is related to the spouse's perception of the patient as being more ill than he or she really is, an attitude that may further push the patient into an indifferent noncompliant sick role. Patient compliance is related to the spouse's perception of the patient as being healthier than he or she really is, a perception that may further reinforce a healthy life engaging behavior.

Another intriguing finding related to compliance and marital adjustment involves some racial differences. This study has found black spouses, and particularly male spouses, to score significantly less on the LMQ than the rest of the sample. Similar findings have been found by Tucker, James, and Turner (in press) who investigated a healthy sample. One possible explanation for this phenomenon is the inappropriate standardization of the original test. The LMQ was normed on a small, middle class, white sample and, thus, may be rather limited and insensitive when applied to other ethnic groups.

Another possible explanation of the finding that black spouses, and specifically black, male spouses score significantly less on the LMQ may be that black males reacted differently to the conditions created by their wives' sickness. History attests to the position of the black woman in the family; it has traditionally been one of being both a working breadwinner and a homemaker. One may assume that within the ranks of the lower SES, black subjects, which this study has investigated, some of the traditional sex-roles are still prevalent. For black males, then, it may have been much more difficult to adjust to an ailing, dysfunctional wife than it was for the rest of the sample.

One other finding to note in this context is that although the LMQ score was negatively correlated with weight gain and with overall compliance scores, blacks, who generally scored lower on the LMQ, did not differ from whites as far as their compliance to the dietary regimen was concerned.

Three possible explanations for this apparent discrepancy could be considered. The first one is that, despite the greater marital dissatisfaction some of the black spouses might have experienced in conjunction with the serious sickness that had afflicted their spouse, they still continued to accept and support the patients and their compliant behavior. The second

explanation is that black patients, and specifically black female patients, may not have expected as much of their spouses in response to their sickness, as white female patients may have expected, and thus were less affected by their spouses' lower marital adjustment. It can be argued that black females are more independent from their spouses than black males are, and thus, when the black female spouse ails, her husband reacts with increased marital maladjustment while she adjusts relatively well to her sick role and does not differ from her white counterpart in her level of compliance. A third alternative explanation for this apparent paradox is that black females are more conforming and complying to a medical authority than the rest of the sample and that this tendency balances the negative effects of their husbands' poor marital adjustment.

Analysis of the different life-engagement scores and their relationship to the compliance variables revealed a mixed picture. When the individual life engagement scores were related to the compliance variables, only one significant (negative) relationship was found: between REC and K. However, examination of the stepwise analyses reveals that even when stringent criteria for entry are imposed, all three measures are entered, with SOC and REC being the most frequently included in the regression equations. The general picture emerging from this analysis

is that the more engaged a patient is in different activities, the lower the likelihood that he or she will abuse the dietary regimen. The likelihood that a patient would be actively engaged in such activities was, in turn, negatively related to the patient's age, time on dialysis and perceived level of medication. The explanation for the latter set of correlations seems quite straightforward. The older the patient becomes, the longer he or she is on dialysis, or the more complicated the patient's medical condition is, the less energy the patient is capable of allocating to the active control and engagement in the various aspects of life. It is felt, however, that the contribution of these life engagement variables and the marital adjustment variable to the accounted variance of the dependent variables might all be explained by a different theoretical framework: cybernetic or control theory.

Carver and Scheier (1982) refer to control theory as a general approach to the understanding of self-regulating systems. The breadth of application of this theory to such diverse areas as economics (Pindyck, 1973), medicine (Guyton, 1976) or engineering (Ogata, 1970) have led people such as Von Bertalanffy (1968), and Miller (1978) to argue that control processes are ubiquitous and identifiable in virtually any sort of self-regulating system. This theoretical framework which was later adopted by such family psychotherapists as Salvador Minuchin, is known as the general systems theory.

The basic unit of cybernetic control according to Carver and Scheier (1982) is the negative feedback loop (see figure 4). Its function is to negate, or reduce, sensed deviations from a comparison value. The INPUT FUNCTION is the sensing of a present condition. That perception is then compared against a point of reference via a mechanism called a COMPARATOR. If a discrepancy is perceived between the present state and the reference value, a behavior is performed, the goal of which is to reduce the discrepancy. This behavior is called OUTPUT FUNCTION. The behavior does not counter the discrepancy directly but by having an impact on the system's environment. Such an impact creates a change in the present condition, leading to a different perception, which in turn is compared with the reference value again. The overall purpose of this closed loop of control is to minimize deviations from the standard of comparison.

As a concrete example of how this theory can be applied to marital adjustment and chronic disease, consider the following. A man senses his wife does not respect his individuality. This perception is then compared against his previous experiences and against his ideal of a marital relationship. A discrepancy is perceived and he decides to talk with his spouse about his feelings in order to reduce the discrepancy. This conversation sensitizes his wife to her husband's feelings, and enhances

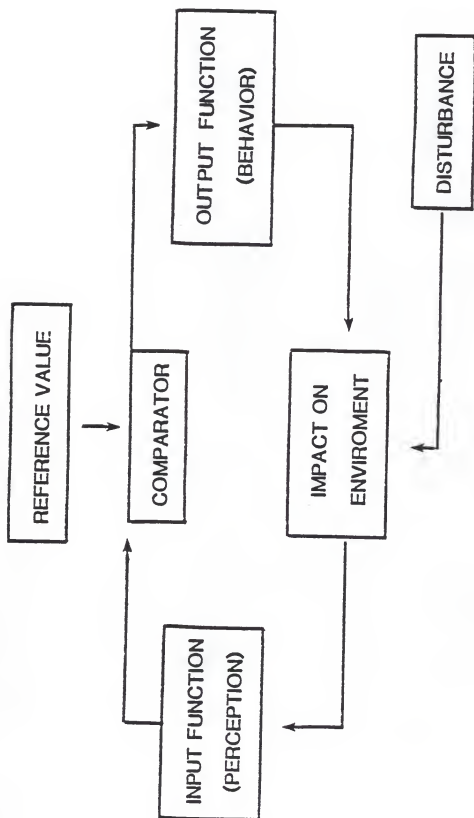


Figure 4

The negative feedback loop -- The basic unit of cybernetic control

the general atmosphere in the relationship. A change has been created in the environment, leading to a different perception, which in turn is compared anew with the reference value.

All of the component processes of Figure 3 were used in this example: perception, comparison, reference value, behavioral output, and the effect of the behavior on the environment. One element of figure 4, however, has not yet been addressed:

DISTURBANCE. Forces from the outside can impinge upon any system that does not exist in a complete vacuum. In this example, having to be involved in chronic hemodialysis treatment could be a major external disturbance to the system, changing the situation both objectively and subjectively in a rather dramatic fashion. The patient is forced into a strong dependency relationship with the machine, the medical staff, and in many cases with his or her spouse. The couple is forced into a mutual role-change process. Self and mutual perceptions change and the patient's sense of control is severely infringed upon.

Having to decrease the discrepancy between the perceived situation and the reference value under these new conditions might become a much more difficult task. The person might try to use some of the correcting behaviors that are familiar to him or that may have worked before under totally different circumstances, but may perceive minimal, if any, decrease in the discrepancy. In fact, many patients in similar circumstances may find that their corrective behaviors are associated with an increased

discrepancy between the reference value and the current situation. What they might never realize is that the disturbance to the system is so severe, that their output functions make no difference at all. Coming back to the example, the man may talk with his spouse about his dissatisfaction, and she, in fact, may try to be more sensitive to him. However, a major life-threatening disturbance to the system, such as chronic renal failure, forces such structural changes that the person may end up feeling his output function (correcting behavior) makes no difference, and that his spouse, if anything, is more "bossy" than ever.

Control theory, then, offers an explanatory theoretical framework to the findings of this study. According to the theory, for some people the sickness constitutes such a disturbance to their internal, and interpersonal systems that it precludes all these initial attempts to decrease whatever discrepancies from their reference values they may have detected. These patients can lose confidence in their sense of control because the disturbing forces work against the discrepancy-decreasing behaviors. It is suggested that this is the point where compliers and non-compliers develop their respective styles. Those among the patients who have learned, either through past experience, or through trial-and-error that they can decrease discrepancies in various spheres of life in spite of the sickness will regain

confidence and a sense of mastery. They will continue to be actively engaged in controlling different aspects of their lives. They will rehabilitate themselves vocationally, will be engaged in recreational and social activities, will continue to enhance their marital relationship, and will take control over their medical regimen. Those, in turn, who have inferred that they cannot make a difference in decreasing the discrepancy will tend to develop a much more withdrawn, disengaged lifestyle that would reflect a relinquishment of control. These patients will then be less engaged in vocational, recreational or social behaviors. They will invest less in the enhancement of their marital life, and will be less in control of their medical regimen.

The subsidiary analysis of this study produced another interesting finding that is well explained by this cybernetic model. Black patients have been generally found to be less active than white patients. This finding ties in with a known racial prejudice against blacks in the United States. It is not difficult to realize how blacks in this country could lose their sense of control. Decades of slavery and centuries of discrimination have been such a major disturbance to the feedback loops in their lives that many of them, justifiably, have realized that there is little they could do to decrease the discrepancies between their reference values and their difficult life situation.

Practical Applications

The correlational design of this study prohibits direct causal inferences. However, the medical and financial costs related to the problem of patient noncompliance call for at least some tentative practical recommendations.

The results of this study could be applied within a control theory frame of reference. It is believed that the main guideline in applying the results of this study should be the restoration of the sense of control within the noncompliant population. The rationale is complex.

The restoration of a sense of personal control may be beneficial because it reflects on the patient's self-image. According to de Charms' (1968) theory of personal causation, individuals need to feel a sense of mastery and personal competence in their environment, a sensed lack of control is assumed to lead the noncompliers to their disengagement from life. Learned helplessness theory (Seligman, 1975), that is essentially a control theory, deals with reactions to the realization that one's actions and one's reinforcements are independent. Such may be the case during an uncontrollable event as being afflicted with an irreversable renal failure.

Seligman (1975) and de Charms (1968) explain the general motivational state following an uncontrollable event or series of events, and hence the decremental performance in the postevent

period. This study does not presume to be able to identify that original trigger event. It is assumed, however, that the chronic illness could potentially contribute to a lost sense of control.

The relevant practical question is believe to be: how can that lost sense of control be restored? A promising direction could be found in the development of an early preventative intervention package, to be implemented very close in time to the onset of the hemodialysis treatment. Such an intervention program could either be a canned module that would be a part of the early treatment regimen, or it could be based on an individual assessment of the patient's sense of control. The development of such a program should be based upon further research, which will be discussed in the following section of this chapter.

The author of this study has been involved in several workshops for family members of hemodialysis patients, entitled "Living with a hemodialysis patient." Based upon this clinical experience as well as on previous studies (De-Nour & Czaczkes, 1976; Huber, 1981), it seems that there is a genuine need among patients and family members for some structured group counseling opportunities. Such counseling could provide a protected environment for sharing concerns and exploring new ways of enhancing the emotional, interpersonal and functional adjustment of both patients and their family members.

It is believed that a well designed counseling intervention package, administered early in treatment, as a preventative measure, could help reduce some of the future medical complication and hospitalization costs most of the noncompliers inevitably face. Given the high rates of regimen abuse among chronic patients (Sackett & Snow, 1979) it is estimated that such a program could not only improve the quality of life of many thousands of chronically ill people, but also save hundreds of thousands of dollars worth of unnecessary medical expenses.

Suggestions for Further Research

1. In view of the paucity of literature relating life-engagement variables to patient compliance and the importance of the generalizability of the results, it is recommended that this study be replicated incorporating the following revisions and additions:
 - a) Within the subject sample population it is suggested that a continued effort be made toward diversity in chronic illness.
 - b) It is recommended that spouse assessment of patient life engagement be cross-validated with another valid instrument, or with direct observations.
 - c) It is suggested that additional biomedical measures of dietary abuse be included, provided they are sensitive to minority cuisines.

- d) The use of a marital adjustment test that has been standardized on a diversified ethnic population is strongly recommended.
2. A study should be designed to compare compliance levels of married and single patients.
3. Support for the suggested theoretical framework of this study should be based on answers to the following research questions:
 - a) Is the hypothetical construct, "sense of control", internally valid?
 - b) If it is, how can it be reliably measured?
 - c) Are those measures of the patient's "sense of control" indeed closely related to both life-engagement variables and patient compliance variables?
4. The next phase of research should explore the impact of a counseling module on the patients' sense of control, their life-engagement behaviors and of course, their compliance with the medical regimen.

Conclusion

The overwhelming impression obtained from this study is that patient compliance is a phenomenon that is strongly related to the patients' pattern of interaction with their interpersonal and physical environments. It has been suggested

that the onset of the chronic illness may have seriously challenged the patients' sense of ability to influence their environments. This study argued that noncompliers have never regained that sense. Based on these conclusions it is suggested that it is the psychologists' responsibility to sensitize the medical establishment to the importance of applying this gained knowledge to the benefit of so many thousands of suffering patients and their families.

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APPENDIX A

INFORMED CONSENT FORM

The purpose of this study is to find the relationship between social and marital life of hemodialysis patients and their compliance to the dietary regimen. The procedures for this study do not involve an experimental treatment. Patients' spouses will complete a brief questionnaire and return it in a sealed envelope to the Kidney Center. Individual questionnaires will not be shown to or discussed with other patients, spouses, nurses, or physicians. Your responses will be kept confidential and will be used for research purposes only.

There are no anticipated risks to participants in this study.

The potential benefit to physicians and patients is an increased ability to identify "high risk" noncompliant patients early in treatment. Furthermore, this study may indicate potentially promising directions for improvement of compliance to the treatment regimen through intervention in marital and social life of patients.

If you have any questions regarding this study, please feel free to call me collect at (904) 392-1575 (o) or (904) 371-6418 (h), or call Dr. Carolyn Tucker at (904) 392-1532.

Any spouse who consents to participate in this study may withdraw his or her consent at any time and discontinue participation in the study at any time without prejudice. No monetary compensation will be awarded.

"I have read and I understand the procedure described above. I agree to participate in the study, and I have received a copy of this description."

Participant Date _____

Eli Somer, Ph.D. Candidate
Project Investigator
311 Little Hall, University of Florida
Gainesville, Florida 32611

Dr. Carolyn Tucker, Project Supervisor
Associate Professor and Licenses Clinical Psychologist

APPENDIX B

MARITAL QUESTIONNAIRE

Code Number _____

All the questions can be answered by placing a check next to the appropriate answer. Please fill out all items. If you cannot give the exact answer to a question, answer the best you can. Give the answers that best fit your marriage at the present time. Thank you very much.

1. Have you ever wished you had not married?
 - o. Frequently _____
 - #. Occasionally _____
 - @. Rarely _____
2. If you had your life to live over again would you:
 - o. Marry the same person _____
 - #. Marry a different person _____
 - @. Not marry at all _____
3. Do husband and wife engage in outside activities together?
 - o. All of them _____ @. Few of them _____
 - #. Some of them _____ +. None of them _____
4. In leisure time, which do you prefer?
 - o. Both husband and wife to stay at home _____
 - #. Both to be on the go _____
 - @. One to be on the go and the other to stay at home _____
5. Do you and your mate generally talk things over together?
 - o. Never _____ @. Almost always _____
 - #. Now and then _____ +. Always _____
6. How often do you kiss your mate?
 - o. Always _____ @. Almost never _____
 - #. Now and then _____

7. Check any of the following items that you think have caused serious difficulties in your marriage.

Mate's attempt to control my spending money _____
 Other difficulties over money _____
 Religious differences _____
 Different amusement interests _____
 Lack of mutual friends _____
 Constant bickering _____
 Interference of inlaws _____
 Lack of mutual affection (no longer in love) _____
 Unsatisfying sex relations _____
 Selfishness and lack of cooperation _____
 Adultery _____
 Desire to have children _____
 Sterility of husband or wife _____
 Venereal diseases _____
 Mate paid attention to (became familiar with) another person _____
 Desertion _____
 Non-support _____
 Drunkenness _____
 Gambling _____
 Ill health _____
 Mate sent to jail _____
 Other reasons _____

8. How many things satisfy you most about your marriage?

o. Nothing _____ @. Two things _____
 #. One thing _____ +. Three or more _____

9. When disagreements arise they generally result in:

o. Husband giving in _____ @. Neither giving in _____
 #. Wife giving in _____ +. Agreement by mutual give and take _____

10. What is the total number of times you left mate or mate left you because of conflict?

o. No times _____ #. One or more times _____

11. How frequently do you and your mate get on each other's nerves around the house?

o. Never _____ +. Almost always _____
 #. Occasionally _____ % . Always _____
 @. Frequently _____

12. What are your feelings on sex relations between you and your mate?

o. Very enjoyable_____	+. Disgusting_____
#. Enjoyable_____	%. Very disgusting_____
@. Tolerable_____	

13. What are your mate's feelings on sex relations with you?

o. Very enjoyable_____	+. Disgusting_____
#. Enjoyable_____	%. Very disgusting_____
@. Tolerable_____	

State approximate extent of agreement or disagreement between husband and wife on the following items:

Check One Column
for
Each Item Below

	Always Agree	Almost Always	Occa- sionally Disagree	Fre- quently Disagree	Almost Always	Disagree	Always Disagree
14. Handling family finances (Example: installment buying)							
15. Matters of recreation (Example: going to dances)							
16. Demonstrations of affection (Example: frequency of kissing)							
17. Friends (Example: dislike of mate's friends)							
18. Intimate relations (Example: sex relations)							
19. Ways of dealing with in-laws							
20. The amount of time that should be spent together							
21. Conventionality (Example: right, good or proper conduct)							
22. Aims, goals, and things believed to be important in life							

23. On the scale line below mark which best describes the degree of happiness, everything considered of your marriage. The middle point, "happy" represents the degree of happiness which most people get from marriage, and the scale gradually ranges on one side to those few who experience extreme joy in marriage and on the other to those few who are very unhappy in marriage.

*	*	*	*	*	*	*
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Scoring: Very Unhappy Happy Perfectly Happy

DEMOGRAPHIC AND LIFE ENGAGEMENT QUESTIONNAIRE

133

APPENDIX D-1

GENERAL LINEAR MODELS PROCEDURE
MEANS BY RACE AND SEX

Variables	Race and Sex			
	White Male	White Female	Black Male	Black Female
TOD	48.57	36.75	33.00	60.43
LMQ	108.42	115.25	104.36	90.42
K	4.88	5.40	5.07	4.67
W	4.38	4.27	4.59	5.26
COMP	9.26	9.67	9.66	9.93
VOC	9.14	16.67	4.82	3.83
REC	3.28	5.42	1.09	3.33
SOC	3.28	1.42	3.09	0.33
ACTIV	15.71	23.50	9.00	7.50
MEDO	5.78	5.40	5.67	6.60
MEDS	7.08	4.67	5.60	6.17
MEDDIF	-0.11	0.40	-0.38	0.20

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON TOD

135

Dependent Variable TOD									
Source	DF	SS	MS	F	PR>F	R-sq.	C.V.	Root MSE	TOD Mean
Model	3	5659.99	1886.66	2.06	0.1127	0.086	70.788	30.26	42.75
Error	65	59536.82	915.95						
Corrected Total	68	65196.81							
Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F	
Race	1	491.01	0.54	0.466	1	213.84	0.23	0.63	
Sex	1	156.73	0.17	0.680	1	792.50	0.87	0.355	
Race x Sex	1	5012.25	5.47	0.022	1	5012.25	5.47	0.022	

APPENDIX D-3
EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON SOC

Dependent Variable SOC									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	SOC Mean
Model	3	66.03	22.01	1.28	0.287	0.056	157.334	4.141	2.632
Error	64	1097.78	17.15						
Corrected Total	67	1163.81							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	0.83	0.05	0.826	1	4.932	0.29	0.593
Sex	1	62.81	3.66	0.060	1	64.636	3.77	0.056
Race x Sex	1	2.38	0.14	0.710	1	2.383	0.14	0.71

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON REC

137

Dependent Variable REC									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	REC Mean
Model	3	153.08	51.03	3.21	0.028	0.13	134.911	3.987	2.955
Error	64	1017.78	15.90						
Corrected Total	67	1170.87							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	91.24	5.74	0.019	1	55.266	3.48	0.066
Sex	1	61.81	3.89	0.053	1	57.754	3.63	0.061
Race x Sex	1	0.04	0.00	0.961	1	0.037	0.00	0.961

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON VOC

138

Dependent Variable VOC									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	REC Mean
Model	3	1240.078	413.359	3.32	0.024	0.135	129.65	11.15	8.602
Error	64	7962.201	124.409						
Corrected Total	67	9202.279							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	760.001	6.11	0.016	1	888.964	7.15	0.009
Sex	1	261.465	2.10	0.152	1	129.112	1.04	0.312
Race x Sex	1	218.611	1.76	0.189	1	218.611	1.76	0.189

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON ACTIV

Dependent Variable ACTIV									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	REC Mean
Model	3	1966.30	655.433	3.39	0.02229	0.137	97.919	13.89	14.19
Error	64	12358.21	193.097						
Corrected Total	67	14324.51							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	1446.507	7.49	0.008	1	1557.932	8.07	0.006
Sex	1	259.428	1.34	0.250	1	119.305	0.62	0.434
Race x Sex	1	260.364	1.35	0.249	1	260.364	1.35	0.249

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON LMQ

140

Dependent Variable LMQ									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	REC Mean
Model	3	2931.334	977.111	3.92	0.012	0.153	14.820	15.783	106.492
Error	65	16191.912	249.106						
Corrected Total	68	19123.246							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	1509.271	6.06	0.016	1	2714.809	10.90	0.001
Sex	1	20.341	0.08	0.776	1	164.640	0.66	0.419
Race x Sex	1	1401.721	5.63	0.020	1	1401.721	5.63	0.020

EFFECTS OF RACE, SEX, AND THE RACE X SEX INTERACTION
ON K

141

Dependent Variable K									
Source	DF	SS	MS	F	PR>F	R-sq	C.V.	Root MSE	REC Mean
Model	3	3.197	1.065	3.23	0.027	0.129	11.459	0.574	5.01
Error	65	21.425	0.329						
Corrected Total	68	24.622							

Source	DF	Partial SS	F	PR>F	DF	Sequential SS	F	PR>F
Race	1	0.058	0.18	0.674	1	0.929	2.82	0.098
Sex	1	0.368	1.12	0.294	1	0.046	0.14	0.707
Race x Sex	1	2.770	8.40	0.005	1	2.770	8.40	0.005

APPENDIX E-1

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE K:
.15 SIGNIFICANCE LEVEL OF ENTRY

Variable TOD		R=.508	$R^2=0.256$		C(P)=0.511	
	DF	SS	MS	F	Prob>F	
Regression	3	4.658	1.552	5.22	0.0035	
Error	45	13.381	0.297			
Total	48	18.040				

	Order of entry	R-sq after entry	B Value	Std. Err.	Type II SS	F	Prob>F
Intercept			6.219				
AGE	2	.213	-0.013	0.007	1.040	3.50	0.067
TOD	3	.258	-0.004	0.002	0.820	2.76	0.103
REC	1	.169	-0.078	0.020	4.497	15.12	0.0003

APPENDIX E-2

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE K:
 .10 SIGNIFICANCE LEVEL OF ENTRY

Variable REC		R=.4200	R ² =0.168	C(P)=0.518	
	DF	SS	MS	F	Prob>F
Regression	1	3.033	3.033	9.50	0.003
Error	47	15.006	0.319		
Total	48	18.04			
	B Value	Standard Error	Type II SS	F	Prob>F
Inter- cept	5.160				
REC	-0.057	0.018	3.033	9.50	0.003

APPENDIX E-3

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE W:
 .15 SIGNIFICANCE LEVEL OF ENTRY

Variable	VOC	R=.756	R ² =0.546	C(P)=3.623		
	DF	SS	MS	F	Prob>F	
Regression	5	85.521	17.104	10.39	0.0001	
Error	43	70.758	1.645			
Total	48	156.280				

	Order of entry	R-sq after entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter- cept			10.792				
AGE	2	.315	-0.040	0.020	6.199	3.77	0.058
MEDS	4	.518	0.289	0.092	16.022	9.74	0.003
VOC	5	.547	0.032	0.019	4.516	2.74	0.104
SOC	3	.444	-0.234	0.063	22.700	13.80	0.0006
LMQ	1	.191	-0.049	0.010	34.030	20.68	0.0001

APPENDIX E-4

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE W:
 .10 SIGNIFICANCE LEVEL OF ENTRY

Variable MEDS		R=.7199	R ² =0.518		C(P)=4.65		
	DF	SS	MS	F	Prob>F		
Regression	4	81.004	20.251	11.84	0.0001		
Error	44	75.275	1.710				
Total	48	156.28					
	Order of entry	R-sq after entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter-cept —			12.731				
AGE	2	.315	-0.061	0.016	22.74	13.29	.0007
MEDS	4	.518	0.219	0.084	11.60	6.78	.012
SOC	3	.444	-0.230	0.064	21.92	12.81	.0009
LMQ	1	.191	-0.049	0.011	33.70	19.70	.0001

APPENDIX E-5

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE COMP:
 .15 SIGNIFICANCE LEVEL OF ENTRY

Variable	VOC	R=.746	R ² =0.557	C(P)=5.7			
	DF	SS	MS	F	Prob>F		
Regression	2	26.925	4.487	8.81	0.0001		
Error	42	21.400	0.509				
Total	48	48.326					

	Order of Entry	R-sq after Entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter- cept			8.030				
AGE	2	.275	-0.028	0.011	2.946	5.78	0.020
MEDS	5	.518	0.145	0.051	4.002	7.85	0.007
VOC	6	.557	0.018	0.010	1.397	2.74	0.105
SOC	3	.409	-0.116	0.036	5.231	10.27	0.002
REC	4	.474	-0.043	0.025	1.479	2.90	0.095
LMQ	1	.137	-0.026	0.006	9.559	18.76	0.0001

APPENDIX E-6

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE COMP:
 .10 SIGNIFICANE LEVEL OF ENTRY

Variable MEDS		R=.7199	R ² =0.518	C(P)=5.782		
	DF	SS	MS	F	Prob>F	
Regression	5	83.031	16.606	9.25	0.0001	
Error	43	77.168	1.794			
Total	48	160.200				

	Order of Entry	R-sq after Entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter- cept			18.638				
AGE	2	.275	-0.076	0.017	32.850	18.31	0.0001
MEDS	5	.518	0.171	0.086	7.047	3.93	0.053
SOC	3	.409	-0.195	0.068	14.768	8.23	0.006
REC	4	.474	-0.106	0.048	8.757	4.88	0.032
LMQ	1	.137	-0.044	0.011	27.565	15.36	0.0003

APPENDIX E-7

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE COMP2:
 .15 SIGNIFICANCE LEVEL OF ENTRY

Variable TOD		R=.738	$R^2=0.545$		C(P)=6.242	
	DF	SS	MS	F	Prob>F	
Regression	6	87.362	14.560	8.40	0.0001	
Error	42	72.837	1.734			
Total	48	160.200				

	Order of Entry	R-sq after Entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter- cept			19.189				
AGE	2	.299	-0.078	0.017	34.818	20.08	0.0001
TOD	6	.545	-0.012	0.007	4.331	2.50	0.121
MEDS	4	.499	0.225	0.091	10.483	6.05	0.018
SOC	3	.435	-0.191	0.067	14.064	8.11	0.006
REC	5	.528	-0.134	0.050	12.245	7.06	0.011
LMQ	1	.164	-0.045	0.011	29.223	16.85	0.0002

APPENDIX E-8

STEPWISE REGRESSION PROCEDURE FOR DEPENDENT VARIABLE COMP2:
 .10 SIGNIFICANCE LEVEL OF ENTRY

Variable MEDS		R=.706	R ² =0.499	C(P)=6.686		
	DF	SS	MS	F	Prob>F	
Regression	4	24.127	6.031	10.97	0.0001	
Error	44	24.199	0.549			
Total	48	48.326				

	Order of Entry	R-sq after Entry	B Value	Std. Err.	Type II SS	F	Prob>F
Inter- cept			8.704				
AGE	2	.299	-0.035	0.009	7.807	14.20	0.0005
MEDS	4	.499	0.113	0.047	3.096	5.63	0.022
SOC	3	.435	-0.130	0.036	7.068	12.85	0.0008
LMQ	1	.164	-0.025	0.006	9.382	17.06	0.0002


BIOGRAPHICAL SKETCH

Eliezer (Eli) Somer was born on August 26, 1951, in Haifa, Israel. He graduated from the Hebrew Gymnasium high-school in Jerusalem, Israel, in 1969, and shortly afterward joined the Israel Defense Forces. Eli is a combat veteran of two Middle-Eastern wars.

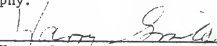
He earned his Bachelor of Arts degree in both psychology and sociology from the University of Haifa in 1974. He received his Master of Arts degree in clinical psychology from that university in 1980.

In 1981, against all odds, Eli left a tenured job and a private practice in Israel, and came with his family to the University of Florida to pursue his doctoral education. Eli is happily married to Liora and a father of three beautiful children.

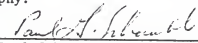
I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Carolyn Tucker, Chairperson
Associate Professor of Psychology


I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Harry Grater
Professor of Psychology

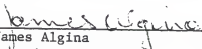
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Paul Schauble
Professor of Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Robert Ziller
Professor of Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


James Algina
Associate Professor of Education

This dissertation was submitted to the Graduate Faculty of the Department of Psychology in the College of Liberal Arts and Sciences and to the Graduate School, and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August, 1984

Dean for Graduate Studies and
Research